

## DOCTOR OF PHILOSOPHY

### Punjabi Sikh Women's Arthritis Self-management Experiences

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# **Punjabi Sikh Women's Arthritis Self-management Experiences**

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***A thesis submitted in partial fulfilment of the University's  
requirements for the Degree of Doctor of Philosophy***

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Arthritis Research Campaign



Coventry University





# Abstract

Self-management interventions enhance the health self-management techniques and physical and psychological health outcomes among people with long-term health conditions (LTHCs). Few individuals from South Asian backgrounds attended the pilot phase of one such intervention: the Expert Patients Programme (EPP), a community-based self-management course. This raised concerns about exacerbating health inequalities. South Asian people have increased prevalence and severity of certain musculoskeletal conditions, yet little is known about their experiences of living with and self-managing these.

This research aimed to rectify these omissions, by describing Punjabi Sikh women's experiences of living with and self-managing arthritis, and identifying barriers and facilitators to EPP. Three studies explored White and Punjabi Sikh EPP tutors' experiences of delivering EPP to South Asian attendees, and Punjabi Sikh women's experiences of living with and self-managing arthritis, both before and after they attended a Punjabi-language EPP.

White and Punjabi Sikh tutors' sometimes dichotomous experiences of delivering EPP to South Asians, captured barriers to South Asian people's attendance, engagement and self-management. Facilitators identified included the need for sensitive tailoring of the Course, involving the Punjabi Sikh community. The Punjabi Sikh women's vibrant experiential accounts revealed the detrimental psychological and physical consequences that arthritis had upon their lives. Highly versatile in their proactive arthritis self-management prior to attending EPP, participants' refined techniques encompassed combinations of medication and Indian remedies, empowered by their religious and spiritual values. Following EPP attendance, the participants reported psychological and physical improvements in their arthritis. Thus, this Study established Punjabi Sikh

women's inherent acceptance of the concept of self-management, and, notwithstanding its current limitations, the likely appropriateness of EPP.

Every Study represents a novel contribution to knowledge. Meaningful engagement with Punjabi Sikh community-members may produce a culturally-competent intervention that could better improve this group's physical and psychological outcomes, thus addressing one small area of health inequalities.

## ***Dedication***

In loving memory of Claire Pattison,  
my soul-mate and inspiration for  
25 years, without whom this thesis would  
not exist.

***"It's not a hill, it's a mountain  
As you start out the climb  
Do you believe me, or are you doubting  
We're gonna make it all the way to the light"***

Hewson, 2009. I'll Go Crazy If I Don't Go Crazy Tonight. U2, No Line On The  
Horizon Mercury Records Ltd (London)

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Finally, I need to thank my husband, Dave, for your tolerance, understanding and unerring confidence in me, especially during the times of adversity.

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# Abbreviations

**Table 0.1: Abbreviations, listed alphabetically**

<b>Abbreviation</b>	<b>Unabbreviated</b>
ARC	Arthritis Research Campaign
ASMP	Arthritis Self-Management Programme
BHF	British Heart Foundation
BME	Black and Minority Ethnic
BPS	British Psychological Society
CA	Conversation Analysis
CAM	Complementary/Alternative Medicine
CC	Cultural competence
CDSMC	Chronic Disease Self-Management Course <sup>1</sup>
CEC	Commission of the European Communities
DA	Discourse Analysis
DoH	Department of Health
EPP	Expert Patients Programme
EPP-CiC	Expert Patients Programme Community Interest Company
EU	European Union
FG	Focus Group
GP	General Practitioner
GT	Grounded Theory
HPS	Health Promotion Specialist
IMIA	International Medical Interpreters Society
IPA	Interpretative Phenomenological Analysis
IT	Information Technology

<sup>1</sup> Also known as the Chronic Disease Self-Management Programme (CDSMP)

<b>Abbreviation</b>	<b>Unabbreviated</b>
LTHC	Long-term health condition <sup>2</sup>
ME	Minority Ethnic
MSD	Musculoskeletal diseases
NHS	National Health Service
OA	Osteoarthritis
ONS	Office for National Statistics
PALS	Patient Advice Liaison Service
PCT	Primary Care Trust
RA	Rheumatoid arthritis
RCT	Randomised Control Trial
SAHF	South Asian Health Foundation
SMP	Self-management Programme
STIs	Sexually Transmitted Infections
UK	United Kingdom
US	United States
USA	United States of America
WHO	World Health Organisation

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<sup>2</sup> Other researchers use terms including long term conditions, chronic conditions, chronic disease, etc.

# Chapter One: Introduction

## Chapter Contents

### 1.1 Background

### 1.2 Context and rationale

### 1.3 Aims and objectives

### 1.4 Summary and Structure of thesis

#### 1.1 Background

The research team of the Self-Management Programme at the Applied Research Centre for Health and Lifestyle Interventions, Coventry University, have been instrumental in establishing a national evidence base for the Arthritis Self-management Programme (ASMP) and Chronic Disease Self-management Course (CDSMC). Now known as the Expert Patients Programme (EPP), it aims to improve the abilities of people with long term health conditions (LTHCs) to better self-manage their lives. The team's extensive evaluative expertise since the introduction of these interventions in the UK has been internationally recognised, with particular reference to the contribution of their qualitative work (Jones, 2010).

At the time of the pilot phase of the EPP, one area of urban deprived Coventry had an Indian population of approximately 48 per cent (Office for National Statistics, ONS, 2001), yet local demographic data showed that not one person from a South Asian background attended the EPP pilot in this district. With concordant anecdotal evidence from research partners and EPP tutors around the country strongly suggesting that this pattern was mirrored elsewhere, the urgent need to undertake research to establish the underlying reasons why

people from minority ethnic (ME) backgrounds were not attending the Course was confirmed.

In this way, potential barriers and facilitators to EPP attendance could be addressed, thus tailoring the course to better meet the cultural needs of people from ME backgrounds. This may, in turn, ensure equitable access as EPP is implemented nationally, so addressing the concerns that were voiced about EPP inadvertently exacerbating the already substantial health inequalities faced by some members of ME groups in the UK.

I began this PhD as a student funded by Coventry University's Faculty of Health and Life Sciences. Having undertaken the first part of the research, I responded, with the support of my supervisory team, to a Call for Proposals by the Arthritis Research Campaign. I was awarded an Educational Research Fellowship, which has supported my studies since 1<sup>st</sup> January 2007.

## **1.2 Context and rationale**

### **1.2.2 Policy evidence overview**

Non-communicable diseases seriously impact upon the quality of life of affected individuals and create large adverse economic effects (World Health Organisation: WHO 2005; Fuster and Voûte, 2005). The WHO advocates the use of psycho-educational self-management interventions, to help reduce the burden of suffering created by LTHCs, with Governments expected to assist the most vulnerable members of society. In England, the Department of Health (DoH) has produced a series of White Papers that aim to promote self-management of LTHCs, and announced the national implementation of EPP (DoH 2004a), with a target of 100,000 course places per year by 2012 (DoH, 2006).

The UK has widening health inequalities (WHO, 2005) that may be attributable to inequities in educational level, psychosocial stress, limited food choice, and inadequate access to healthcare and health education (WHO, 2005; Commission on Social Determinants of Health - CSDH, 2008); examples of health inequalities are given shortly. People from ME backgrounds are recognised as being at risk (WHO, 2005; CSDH, 2008; Commission of the European Communities (CEC, 2009). In order to address these health inequalities, the CEC (2009) advocated that the health needs of people from ME backgrounds must be considered. The 'one size fits all' policy approaches were recognised as unlikely to be effective amongst ME groups (CEC, 2009). In the UK, the Race Relations (Amendment) Act (Home Office, 2000) and Equality Bill (2009) require NHS organisations to directly address ME health issues when developing and implementing policies, in order to reduce ME health inequalities.

Many of the DoH policy documents that introduced EPP, recognised a historic inequity in healthcare access and experience among people from ME backgrounds and propose methods to overcome this during EPP's implementation. For example, the active participation of local communities and voluntary groups (DoH, 2004b), and meaningful inclusion of local community members, may ensure culturally tailored courses meet their specific needs.

### **1.2.3 ME health inequalities overview**

The previous section confirmed that the importance of self-management education for people with LTHCs is internationally and nationally recognised. Such interventions need to be implemented in close association with ME communities as this may help to reduce health inequalities amongst these groups. This section gives examples of the type of health inequalities that people from ME backgrounds experience in the UK, possible causes and potential solutions.



Indian women in the UK are 2.5 times more likely to report having a LTHC than White women (Evandrou, 2000) and South Asian people in the UK are up to six times more likely than White people to have diabetes (South Asian Health Foundation (SAHF)/Diabetes UK, 2009). A UK survey of South Asian and White people found that significantly more South Asians with musculoskeletal conditions reported widespread pain (MacFarlane et al., 2005); similarly, Allison et al. (2002) found that musculoskeletal symptoms were more common among people from ME groups, and pain in multiple joints was more prevalent among some South Asian people than in the White population. In their UK survey, Palmer et al. (2007) reported the prevalence of widespread pain in Punjabi Indians was 22%, compared with nine per cent in European participants.

Cultural differences in risk factors may explain some of these variations on disease prevalence, such as elevated levels of smoking amongst some Pakistani and Bangladeshi men compared with White or Indian men (Evandrou, 2000). Minority Ethnic groups also have varying patterns of healthcare system usage for example, low uptake rates of some screening and preventative health care strategies (Moudgil and Honeybourne, 1998), which may further contribute to inequalities. Burr (2002), Siriwardena (2004) and Evandrou (2000) argued that the consequences of direct and indirect racism may influence health and experiences of healthcare. Medication perceptions can vary between ethnic groups, which may affect outcomes (Kumar et al., 2008). Similarly, Singh (2004) found that ME people did not understand the causes of diabetes, nor the purpose or importance of, when to take medication during the day, or why.

Numerous studies have shown that educating patients increases their knowledge and improves health (Dein, 2004). Health education resources that are tailored to the cultural needs of target communities, for example to consider ethnicity-specific health beliefs, are more likely to have 'real practical value' (Samanta et al., 2009; Brach and Fraser, 2001). Evidence supports the

effectiveness of such culturally tailored health education amongst South Asians with low levels of literacy and health literacy (Hawthorne, 2001; McAvoy and Raza, 1991). In a diabetes educational intervention, in the Foleshill area of Coventry, knowledge was essential to successful self-management (Singh, 2004).

#### 1.2.4 EPP overview

The previous section confirmed the scope of health inequalities some ME people experience, potential causes and possible solutions, including culturally tailored self-management education. This section outlines effectiveness evidence around self-management educational interventions.

Developed by Professor Kate Lorig and colleagues at Stanford University's Patient Education Research Center, the intervention follows the 'Stanford Model' of patient self-management education. The benefits of the Arthritis Self-Management Program (ASMP) - known as the 'Challenging Arthritis' course in the UK - were recognised as potentially helpful to patients with other LTHCs. The Chronic Disease Self-Management Course (CDSMC) was developed and is being implemented as the 'Expert Patients Programme' (EPP) across England by the EPP Community Interest Company (EPP-CIC). Figure 1.1 shows this evolution of EPP in the UK from its origins, in the US:



**Figure 1.1: Evolution from ASMP to EPP**

The EPP is a group-based self-management intervention, delivered in the community, by pairs of trained lay-tutors who have a LTHC themselves. Grounded in the psychological principles of self-efficacy (Bandura, 1977), these structured courses comprise six, weekly sessions, each lasting 2½ hours. The multi-component topics covered include: an overview of self-management

principles, communication with family and health professionals, nutrition and exercise, cognitive symptom management, dealing with depression, and contracting. It encourages people to take responsibility for their own health needs and provides them with the confidence, skills and knowledge to change their behaviour and take more control of their lives with their conditions.

### **Self-management evidence overview**

Barlow et al. (2002)'s review concluded that self-management programmes are effective in increasing knowledge, symptom management, use of self-management behaviours and self-efficacy, and promote beneficial medical outcomes (Barlow et al., 2002). Warsi et al. (2004)'s systematic review and Chodosh et al. (2005)'s meta-analysis, both found that diabetic attendees demonstrated improvements in haemoglobin levels and systolic blood pressure levels, asthmatic attendees had fewer attacks and pain and function improved amongst osteoarthritis (OA) patients. Both Newbould et al. (2006)'s review and Foster et al. (2007)'s Cochrane review concluded that lay-led self-management programmes potentially lead to small, short-term improvements in participants' self-efficacy, self-rated health, cognitive symptom management, and frequency of aerobic exercise. Together these provide evidence that self-management programmes can improve some psychological and physiological outcomes. Similarly, Newman et al. (2004)'s review found that arthritis interventions led to some improvement in self-reported symptoms and disability measures and identified behaviour-change as the most successful outcome across the arthritis, asthma and diabetes disease groups.

### **ASMP evidence overview**

The condition-specific Arthritis Self-management Programme includes some condition-specific guidance, in addition to the content outlined above, and has attracted evidence of its effectiveness. Barlow, Turner and Wright's (2000) RCT found attendees had significant improvements in self-efficacy, symptom

management and reduced pain and significantly greater health behaviour performance in communicating with health-care professionals, dietary habit, exercise and relaxation compared to a waiting-list Control Group, four and 12 months after completing the course. At 12-month follow-up, statistically significant improvements on pain and a decrease in visits to GPs were also identified. Improvements in self-efficacy, positive and negative affect, anxious and depressed moods, pain and fatigue, cognitive symptom management and communication with physician were maintained eight years after attending ASMP (Barlow, Turner, Swaby et al., 2009). In another UK RCT of ASMP, Buszewicz, Rait, Griffin et al. (2006) performed twelve-month follow-ups with attendees. Attendance reduced anxiety and increased self-efficacy for managing pain and other arthritis related symptoms. Qualitative evidence shows that ASMP provides participants with 'tools' to change the way they manage their condition, which may, for example, have important implications for health-related quality of life and ability to maintain employment or independent living (Turner, Barlow and Williams, 2000). Attendees appreciated meeting similar others, the opportunity for social comparison, were using self-management techniques such as goal-setting, and felt more in control of their lives (Barlow et al., 2009).

### **CDSMC evidence overview**

Lorig, Sobel, Stewart et al. (1999) performed a six month RCT of CDSMC in the USA. Attendees were exercising more, better managing their cognitive symptoms, reported improved communication with health care professionals, and self-reported improvements in health, health distress, fatigue, disability, and social/role activities limitations, compared with controls. They also had fewer hospitalisations and days in hospital than controls (Lorig et al., 1999). Similarly, Lorig, Ritter, Stewart et al. (2001) at one and two year follow-ups, found emergency hospital admissions, outpatient visits and self-rated health distress were all significantly reduced, whilst self-efficacy significantly improved.

International research also confirms the effectiveness of the CDSMC for use in ME groups. For example, Lorig, Ritter and González (2003) evaluated a Spanish-language course for use with US Hispanics, who had significantly improved health status, health behaviour, self-efficacy, and fewer emergency hospital visits, at four-month follow-up. These improvements were maintained and remained significantly different from baseline, at 12-month follow-up. Australian research qualitatively investigated the extent to which the Course required modification so that concepts around self-management could be made more relevant to Vietnamese, Greek, Chinese and Italian communities. Conceptual aspects of the course required little modification, with myths around the importance of fatalism dispelled. Yet high levels of illiteracy in participants' own language and in English required the course materials to be made accessible and equitable for non-English speakers (Walker, Weeks, McAvoy et al., 2005). The same team then conducted an RCT on the four versions of CDSMC in Chinese, Italian, Greek or Vietnamese (Swerissen, Belfrage, Weeks et al., 2006). At six-month follow-up, intervention group participants had significantly higher scores than controls on energy, exercise, symptom management, self-efficacy, general health, pain, fatigue and health distress (Swerissen et al., 2006).

### **EPP evidence overview**

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Kennedy, Gately, Rogers et al. (2004) undertook a national evaluation of the EPP pilot process across the UK. Ensuring equity of access to people in deprived neighbourhoods and those from ME backgrounds, were identified by many Trusts as areas requiring attention (Kennedy et al., 2004). At the time of the study, EPP was only deliverable in English, which excluded many potential attendees, although translation of course materials and production of an audiotaped version had begun. In their RCT, Kennedy et al. (2007) found that, compared with controls, attendees had significantly increased self-efficacy, energy and health-related quality of life at six-month follow-up; a small cost saving was also identified.

## **ME EPP evidence overview**

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In the only RCT of the EPP for ME communities to date, the EPP, tailored for Bangladeshi Muslims, yielded improvements in self-efficacy, cognitive symptom management and improved depression scores (Griffiths, Motlib, Azad et al., 2005). However, unpublished qualitative data revealed that participants' faith was a potential barrier to successful self-management. For example, participants understood that doctors were not responsible for their future, but Allah was, and that illness and hardship were tests from Allah, or punishment for sins. Griffiths et al. (2005) argued for further research to consider these issues.

### **Summary**

Concerns were raised about exacerbating ME health inequalities when consistent anecdotal evidence identified that few South Asian people attended EPP's pilot phase; policy suggests meaningful community collaborations to overcome this. Arthritis prevalence and severity is greater amongst South Asian people living in the UK than in the majority White population (Allison et al., 2002; MacFarlane et al., 2005; Palmer et al., 2007), yet little is known about South Asian community-members' experiences of living with and self-managing arthritis, or what may influence these. The only EPP study with South Asians revealed substantial barriers may exist for South Asian people to practice self-management, including engaging with EPP principles.

Thus, the context and rationale for this research is positioned at the intersection of the three arenas of policy, ME health inequalities and self-management, in order to explore South Asian people's LTHC self-management experiences.

### 1.3 Aims and objectives

#### 1.3.1 Aim:

The primary aim of this research was:

***to describe the experiences of living with a LTHC, identifying barriers to and facilitators of self-management practices, including attendance on a self-management programme, amongst people from South Asian backgrounds.***

#### 1.3.2 Objectives:

- i. Describe non-minority tutors' experiences of delivering Expert Patients Programme (EPP) courses that have included attendees from South Asian backgrounds;
- ii. From the perspective of tutors from South Asian backgrounds, describe the experiences of delivering EPP courses that have included attendees from South Asian backgrounds;
- iii. Describe Punjabi Sikh women's experiences of living with osteoarthritis or rheumatoid arthritis;
- iv. Identify perceived barriers and facilitators to Punjabi Sikh women's self-management practices, including attendance on a self-management programme;
- v. From the perspectives of Punjabi Sikh women, describe the experiences of attending a Punjabi-language EPP course;
- vi. Describe their subsequent experiences of living with arthritis;

### 1.4 Structure of thesis

This Chapter has introduced the background to my PhD and provided a brief summary of the evidence-based context and rationale behind it. These are

elaborated upon in a more extensive overview of the literature, in Chapter Two. The methodological approach adopted in this thesis is considered in Chapter Three, with particular focus on the methodologically innovative qualitative analysis on translated data. My aims and objectives are detailed above, and Table 1.1 shows the studies that were undertaken in order to achieve these, that are reported in Chapters Four to Seven.

**Table 1.1: Studies, descriptions and chapter numbers**

<b>Study number and objective met</b>	<b>Study description</b>	<b>Chapter number</b>
Study I; objective i	White tutor interviews	Four
Study II; objective ii	South Asian tutor interviews	Five
Study IIIa; objective iii & iv	Punjabi Sikh community interviews, pre-EPP	Six
Study IIIb; objective v & vi	Punjabi Sikh community interviews, post-EPP	Seven

Study I and Study II were multi-perspectival in design. Study I, reported in Chapter Four, involved interviews with White EPP tutors who had delivered an English-language EPP course that included one or more attendee from a South Asian background. Interviews explored participants' experiences with South Asian EPP attendees, identifying tutors' own perceived needs, the perceived needs of South Asian attendees, tutors' socio-political beliefs and knowledge around multi-culturalism in the EPP context, and the potential role of interpreters.

Chapter Five reports Study II, in which I interviewed South Asian tutors who had delivered an EPP course that, again, had included one or more South Asian attendee. The South Asian tutors revealed barriers to South Asian community-



members' attendance on EPP, their comprehension of it, and performance of self-management behaviours were identified. The need for socio-cultural tailoring and recruitment strategies were highlighted.

The third Study was a planned longitudinal design; Study IIIa is reported in Chapter Six and Study IIIb is reported in Chapter Seven. Study IIIa explored Punjabi Sikh community-members' experiences of living with and self-managing arthritis, prior to their attendance on EPP. The physical and psychological consequences of living with arthritis are described, together with participants' vibrant accounts of their self-management practices and influences upon these. Facilitators of and barriers to the Punjabi Sikh women's attendance and comprehension of EPP, and performance of self-management behaviours, were identified, in addition to some ambivalence.

For Study IIIb, interviews were conducted with those Study IIIa participants who had attended a Punjabi-language EPP, and are reported in Chapter Seven. Facilitators to their attendance and engagement with the EPP are highlighted, whilst the physical and psychological improvements arising from enhanced arthritis self-management following their attendance on the Course are described. Participants did not identify any barriers to engagement or comprehension of EPP.

Finally, Chapter Eight discusses the findings of Punjabi Sikh participants' arthritis self-management experiences, including living with arthritis, self-managing arthritis, and barriers and facilitators to EPP, as identified in this thesis. Having discussed methodological considerations raised by this Study, I examine policy, theoretical and methodological implications of this work, before recommending directions for future research.

# Chapter Two: Literature Review

## Chapter Contents

### **2.1 Policy Literature**

### **2.2 ME Health Inequalities**

### **2.3 Self-management Literature**

### **2.4 Chapter Two Summary**

***A discussion of the literature pertinent to the findings that emerged in Study III is presented in Chapter 6.5.***

This Chapter provides an overview of published literature across the domains of policy, ME health inequalities and self-management, that are covered by this thesis, which provide the background rationale for the research. The breadth of this literature precluded a formal systematic literature review across each area, and this overview therefore represents a parsimonious selection of those considered most appropriate.

## **2.1 Policy Literature**

This section outlines documents influencing international and UK policy around LTMC self-management and ME health inequalities, in order to provide the international and national backdrop to this thesis.

### **2.1.1 Definition of terms**

#### **'Long-term health conditions' versus 'Chronic diseases'**

In this section I justify my preference of the term 'long-term health conditions' over others, and explain what constitutes such a condition.

Terms including 'chronic diseases', 'chronic illnesses' and 'chronic conditions' are used interchangeably in the health literature, but have developed negative connotations over recent years. 'Chronic' overlooks the fact that many people living with a LTHC experience both bad days *and* good days, with participants expressing the need to maintain a positive outlook in order to cope with their LTHC (Barlow, Cullen and Rowe, 2002). 'Disease' and 'illness' both have bio-medical associations that have long been challenged in health psychology. The phrases 'long-term conditions' and 'long-term health conditions' (LTHCs) are now gaining favour in the literature.

Differences that can typically exist between LTHCs and acute conditions are highlighted in Table 2.1:

**Table 2.1: Key differences between acute and long-term health conditions**

	<b>Acute conditions</b>	<b>Long-term health conditions</b>
<b>Onset</b>	Abrupt	Commonly gradual
<b>Duration</b>	Limited	Lengthy indefinite
<b>Cause</b>	Usually single cause	Multivariate causation, changing over time
<b>Diagnosis and prognosis</b>	Commonly accurate	Diagnosis often uncertain; prognosis obscure
<b>Technological intervention</b>	Usually effective (lab. testing, imaging, medication, surgery)	Indecisive technologies and therapies with adversities
<b>Outcome</b>	Cure likely with return to normal health	No cure; management over time necessary
<b>Uncertainty</b>	Minimal	Pervasive
<b>Knowledge</b>	Professional knowledgeable; patient inexperienced	Profession and laity partially and reciprocally knowledgeable

**Adapted from Lorig (1996) and Holman and Lorig (2004)**

Whilst clearly simplistic (for the sake of clarity) the final box in this table highlights the ongoing need for collaborative management between people with LTHCs and their healthcare providers, to address the physical and psychological consequences of their LTHC.

For the purpose of this thesis, the expression 'long-term health condition' (LTHC) is therefore my preferred term used in this thesis, to include conditions of an ongoing nature.

### **2.1.2 International Policy**

#### **International LTHC self-management Policy**

The importance of self-management to reduce the burden of LTHCs on societies and individuals is recognised internationally. LTHCs seriously impact upon the quality of life of affected individuals and create large adverse economic effects (WHO, 2005; Fuster and Voûte, 2005). In an example that recognised this, 2000-2010 was declared the WHO's 'Bone and Joint Decade'<sup>3</sup>. The global campaign aimed to raise awareness of the growing burden of musculoskeletal conditions, including arthritis, on society, empower patients to participate in their own care and promote cost-effective prevention and treatment; I return to arthritis-specific evidence later in this thesis. LTHCs are not purely the result of unhealthy lifestyles, WHO argued, as individual responsibility can only be fully effective where equitable access to a healthy life exists. Governments were urged to support people to make healthy choices and provide special protection for vulnerable groups (WHO, 2005); I examine the UK policy context in Chapter 2.1.3.

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<sup>3</sup>See: <http://www.boneandjointdecade.org/default.aspx?contId=216>

Prompted by the United Nation's failure to include LTHC reduction in its 2005 Millennium Development Targets (Horton, 2005; Zarocostas, 2005) and acknowledging the "impending chronic disease pandemic", WHO proposed a framework to address this. The scientific knowledge to reduce LTHCs already exists, by basing interventions on empirical evidence and WHO (2005) recognised that progress had been made in high-income countries including the UK. The WHO (2005) advocated the use of effective LTHC self-management interventions, although Strong et al. (2005) acknowledged their use is neither widespread nor equitable.

### **International health inequalities policy**

The UK has widening inequalities (WHO, 2005; Commission of the European Communities, CEC, 2009), that is the gap between those who enjoy the best health and those who experience the worst. These inequalities may be attributable to inequities in educational level, psychosocial stress, limited food choice, and inadequate access to healthcare and health education (WHO, 2005), may be further exacerbated by factors including poverty, gender and minority ethnic status (CEC, 2009), and by global and national unequal distribution of power (Commission on Social Determinants of Health, CSDH, 2008). The influence of language and cultural health and lifestyle behaviours are recognised (WHO, 2005; CEC, 2009); however, no detailed direction was given as to how these may be addressed. Yet, the positive impact that health interventions can have generally is noted, as is the paucity of evidence supporting their effectiveness amongst different groups. Similarly, the need for more effective data-collection to allow the identification of health inequalities is recognised as important; the inclusion of ethnicity data is again not mentioned specifically (CSDH, 2008; CEC, 2009). Notwithstanding these shortcomings, the acknowledgment that migrants' particular health needs must be considered and that 'one size fits all' policy approaches are unlikely to be effective, are encouraging.

### 2.1.3 UK policy

#### **UK Self-management and EPP policy**

UK policy addresses the use of self-management programmes to successfully deliver life-skills training for people living with LTHCs. Whilst other structured group educational interventions exist (e.g. the Diabetes Education and Self Management for Ongoing and Newly Diagnosed programme - DESMOND), they are beyond the scope of the present thesis, which focuses on EPP.

In 'Saving Lives: Our Healthier Nation' (DoH, 1999), the UK government stated its intention to design, pilot and deliver the EPP in England and Wales. Financial and performance incentives were introduced in 'The NHS Plan' (DoH, 2000), to ensure that the Programme was implemented. 'The Expert Patient' (DoH, 2001) proposed the use of EPP to develop patients' confidence and motivation to use their own skills, knowledge and resourcefulness, in order to take control of their lives with a LTHC (DoH, 2001). The need for patients to have choices around self-management generally, and EPP specifically, was confirmed in 'Generic Choice Model for Long-term Conditions' (DoH, 2007). Self-management was recognised within the context of one part of patient care, also incorporating clinical and psychological support, and social factors, which together support independence. Apparently aimed at NHS commissioners, the report was lacking in detail as to how this may be achieved.

Following publication of encouraging pilot study evaluation data (discussed later; Kennedy, Gately, Rogers et al., 2004), the 'NHS Improvement Plan' (DoH, 2004a) announced the national implementation of the EPP in every PCT by 2008. Self-management, including EPP, was considered the right level of care for 70-80 per cent of people with a LTHC, demonstrating an important shift away from traditional, paternalistic healthcare models (DoH, 2004a). 'Our Health, Our Care' (DoH, 2006), promised a sweeping advancement of EPP,

from 12,000 course places per year to 100,000 by 2012, supported by trebled investment. DoH (2006) announced its radical intention to establish the 'Expert Patient Programme Community interest Company' (EPP-CiC) to market and deliver self-management courses.

The need for meaningful collaboration to successfully implement EPP was recognised as a priority in 'The NHS Plan' (DoH, 2000), which announced increased collaboration between the NHS, Social Services Departments and the private sector. EPP was again advocated as having an integral part in supporting patient choice in the White Paper 'Choosing Health' (DoH, 2004b), which restated the Government's commitment to implementing EPP with the active participation of local communities and voluntary groups. PCTs and Local Authorities were recommended to use Local Strategic partnerships with community and voluntary organisations in order to strengthen multi-agency support and coordination and share their expertise in self-care and self-management (DoH, 2004a).

In 'Improving Chronic Disease Management' (DoH, 2004c), EPP was adopted as the primary model for delivering good disease management. 'Supporting People with Long-Term Conditions' (DoH, 2005a) presented best practice examples of successes from the NHS, social care and international experience, to help develop an integrated and systematic model for managing care for people with LTHCs. The Government again stressed the importance of collaborative working (DoH, 2005a, 2005b). 'Our Health, Our Care' (DoH, 2006) proposed the development of new partnerships with stakeholders in self-care support, by the new EPP-CiC. I discuss the relevance of this emphasis on the need for collaborative working to successfully implement EPP, with reference to ME communities, after outlining the UK policy that relates to ME health inequalities.

## **UK health inequalities policy**

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A number of influential documents which examine how to reduce these health inequalities, including ME inequalities, are considered here. I then consider how they relate to the implementation of EPP for ME groups. The effects of ME health inequalities are contained in Section 2.2.

The Macpherson report (1999) into the death of Stephen Lawrence found 'institutional racism' to be common in some public institutions. This pervasive organisational failure could lead to ME people experiencing substantial disadvantages in services, which, in the healthcare setting, could contribute to health inequalities. The Race Relations (Amendment) Act (Home Office, 2000) was introduced to counter such racism, and required health authorities, health boards, NHS Trusts and primary care trusts to address issues of race and ethnicity in their service provision. The need for such action had already been identified in the NHS: The Acheson report (*Inequalities in health: report of an independent inquiry*, 1998), which called for steps to be taken that included the evaluation of all health policies to ascertain their impact on health inequalities. Similarly, the Wanless report (*Securing Our Future Health: Taking A Long-Term View*, 2002) identified ethnicity as a social determinant of health, and called for detailed patient ethnicity data-collection to allow for intervention evaluation to consider specific groups; CEC (2009) reiterated this call and I return to it shortly. Notwithstanding this identified need for ethnicity data, Sir Michael Marmot, in his Foreword to *"Tackling Health Inequalities: 10 Years On"* (DoH, 2009) acknowledge that this alone would not resolve ME health inequalities:

***"Inequalities in health arise because of social inequalities in society, not simply because of inequalities in healthcare."*** (DoH, 2009; p.1)

However, whilst accepting that the broader social inequalities that cause health inequalities are critically important, they are beyond the remit of the present Study and are not, therefore, considered in this review; I return to '10 years on' shortly.



Many DoH policy documents recognise a historic inequity in health care access and experience among people from ME backgrounds and propose methods to overcome it, which will now be considered. The new Performance Assessment Framework national inequalities target was designed to measure and manage equitable healthcare access for minority groups (DoH, 2000). Citing evidence that South Asian patients showed less knowledge about their LTHC than other patients, *'Building on the Best'* (DoH, 2003) established the Government's intention to offer ME patients information about conditions and treatment options in a choice of community languages and formats.

*'Tackling Health Inequalities: A Programme for Action'* (DoH, 2003b), attempted to stimulate action against health inequalities that are experienced by, for example, people with LTHCs, older people, and those from ME backgrounds, all of whom experience worse health than other groups. The EPP was cited as an example of an intervention that, with effective community collaboration, could serve to address health inequalities. This collaboration might be through BME Patient's Forums, which were established to support and empower local communities 'who have not traditionally been given a voice' (p44), to take action to change issues affecting health. Success would be determined by a reduction in health inequalities by 2010, demonstrated by 10% reductions in infant mortality and improvements in life expectancy; ethnic data would be measured, where available.

However, this reflects an inherent flaw, mentioned in the International policy section of this Chapter, and above: ethnicity data is rarely collected accurately and consistently. This flaw is recognised in the DoH's (2005c) update, which was unable to comment specifically on the role of ethnicity when reporting headline figures. Similarly, in *'Systematically Addressing Health Inequalities'* (DoH, 2008) the need for improved ethnic monitoring was again noted; clearly this ongoing omission needs to become a priority if BME health inequalities are

to be recognised and addressed. Notwithstanding this substantial caveat, the report's assertion that health interventions should be designed and delivered around individuals' needs (i.e. tailored) so that people are not forced to fit service requirements (i.e. 'one size fits all'), with systematic, not tokenistic, community engagement, is encouraging. A major concern of the Health Inequalities initiative is that with incomplete/missing BME data, its findings may serve to compound, rather than resolve ME health inequalities, if policies are designed around participating non-BME groups who experience health inequalities.

'Saving Lives' (DoH, 1999) proposed new ME community-based health improvement Programmes, again through local partnerships. Critically, programmes would be designed through the genuine involvement of ME people, not based on assumptions of what appeared to be required. 'Building on the Best' (DoH, 2003a) again required work with the most disadvantaged and marginalised people through community contacts. The need to develop strong collaborative working partnerships with ME community groups was re-confirmed in 'Choosing Health' (DoH, 2004c). Local communities could positively impact upon health, by providing skills, social networks, motivation, resilience, tradition and cultural support for promoting and protecting health. EPP was given as an example of a service being delivered through community-based initiatives and of health as a way of life (DoH, 2004c). The consultation document, 'Independence, Well-being and Choice' (DoH, 2005c) proposed changes to health and social care in order to better meet the needs of diverse communities, which existing services have not always recognised. Closer working between PCTs, and the independent and voluntary sectors was again suggested, with a preventative approach to improved health and social care, aimed at promoting health, social inclusion and improved quality of life.

Similarly, the need for community and population-level health education interventions tailored around their target audience, considering the social and

cultural context, was recommended by the National Institute for Clinical Excellence (NICE, 2007). Aimed at policy makers (amongst others), advice such as:

(NICE, 2007; page 4)

appears, however, to be a somewhat tokenistic inclusion, given the enormity of these tasks, and that a later recommendation is to evaluate the cost-effectiveness of such interventions.

Recently, the House of Commons Select Committee published its report on health inequalities; in their response to this, the Government acknowledged that the often socially determined causes of health inequalities are deep and ingrained, requiring long-term action to overcome (TSO 2009). Across-Government working was required to effect changes in ME health inequalities, and collaboration between different sectors. Policy initiatives that consider health inequalities must be evidence-based, and have sufficient time to bed in. Yet tensions exist between the recognised urgency of addressing inequalities, and the time it will take to pilot, undertake randomised/paired trials/quasi-experimental research and evaluate health outcomes over time and assess cost-effectiveness of such measures, which are not addressed. The report does not contest the accusation that experiential patient data is 'soft' and should therefore be disregarded as evidence for policy implementation. As the present thesis evidences in its Findings in later Chapters, high quality qualitative data can reveal unexpected insights that may prove eminently suitable for further investigation; I therefore refute the claimed ineffectiveness of such data. Similarly, although the systematic consideration of ME health inequalities is laudable, it may overlook invaluable 'grey data' that is particularly pertinent amongst ME communities.

To mark a decade since the publication of the catalytic Acheson report, DoH (2009) produced *Tackling Health Inequalities: 10 Years On – A Review of Developments*. It assessed developments against the Acheson report, including health indicators, considered lessons learned and future challenges. Confirming Acheson's identification of ethnicity, gender and older age as specific dimensions of health inequalities, this report highlighted the recently introduced Equality Bill 2009. This gives NHS bodies a duty to cover the protected characteristics of age, sexual orientation and religion or belief, and requires them to eliminate unlawful discrimination, whilst advancing equality and fostering good relations. The Bill also requires these bodies to take action to promote health equality, including the health needs of BME communities, within the context of increasing overall health and reducing health inequalities. It further requires local PCTs and local authorities to work collaboratively with local communities through a joint strategic needs assessment to establish the current and future health and wellbeing needs of the population. These local organisations should tackle inequalities, specifically focusing on age, ethnicity, disability, gender, religion and migrant populations. '10 years on' (DoH, 2009) also highlights the recently published NHS Constitution, which informs patients of their legal rights under the Equality Bill. In conclusion, DoH (2009), recommended that ME groups' needs are specifically considered when developing and implementing policies aimed at reducing socioeconomic inequalities, that service development is sensitive to ME people's needs whilst promoting greater awareness of their health risks, and, importantly, that ME groups' needs are specifically considered in needs assessment, resource allocation, health care planning and provision.

The consistency of the need for ME health inequalities to be specifically considered throughout health policy is encouraging, suggesting that the key components necessary to reduce ME health inequalities may have been identified. Yet the fact remains that despite overall improvements in population health (CEC, 2009), health inequalities are widening. The necessity for accurate ethnic data-collection, both by NHS bodies, and health researchers, is

confirmed; without this, the impact of these policies upon ME health inequalities is impossible to measure. Collectively, these publications strengthen the argument that special attention is required to enable ME people with a LTIC to attend EPP.

### **UK EPP and health inequalities policy**

The EPP implementation collaborations, mentioned earlier, are particularly relevant to ME groups. For example, in addition to looking at improving South Asians' poverty of healthcare access through community involvement, NHS policy has also considered the need to identify cultural influencers of South Asian people's health behaviours. 'Choosing Health' (DoH, 2004c), recommended identifying barriers to ensure equitable access allowed the implementation and successful delivery of EPP. This supports WHO's (2005) assertion that people need support to make healthy choices. The necessity to understand different ethnic groups' traditional cultural and health practices, such as appropriate spiritual care and hospital food provision, may assist service improvements to be made ('Saving Lives: Our Healthier Nation', DoH, 1999). 'Independence, Well-being and Choice' (DoH, 2005b) advocated that religious, cultural and ethnic needs of individuals should be addressed through the local development of 'culturally sensitive' services. In 2006, 'Our Health Our Care' stated that the EPP-CiC would design new EPP courses to meet different people's needs, including those in marginalised groups.

At the time of writing, Professor Sir Michael Marmot, Chair of the WHO Commission for Social Determinants, is expected to deliver a Post 2010 Strategic Review of Health Inequalities. The way in which complex challenges around ME health inequalities are meaningfully addressed will be of significance to improving these groups' experiences of living with and self-managing LTICs.

## **Summary**

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The WHO advocates the use of self-management interventions to help reduce the burden of suffering created by LTHCs, with Governments expected to assist the most vulnerable members of society. The consistency of DoH policy backing the use of self-management, including EPP, confirms the UK government's support for EPP. Similarly, the need to actively involve members of ME communities' and identify specific needs in order to improve their health is constant across UK policy documents. Continuing flaws in ethnic data-collection that may exacerbate ME health inequalities are, however, identified.

### **2.2 ME Health inequalities**

The previous section confirmed that the importance of the self-management of LTHCs is recognised internationally and nationally, and that the implementation of EPP must actively seek to address ME health inequalities. This section provides evidence of the types of these inequalities that are experienced by people from ME backgrounds, possible causes and potential solutions. At the outset of this Study, the precise ME group who would be the focus of the research had not been identified; however, the local observation that South Asian people were severely under-represented on the EPP pilot had been noted. As previously highlighted, much research does not consider the differences between highly heterogeneous ME groups. Thus, although South Asian evidence is cited where available, this section considers a broad spectrum of evidence across diverse ethnicities. Similarly, the LTHC of interest had not been identified; the following therefore considers ME health inequalities across a range of LTHCs. Detailed consideration of South Asian inequalities in arthritis is made in Chapter 6.2.1.

#### **2.2.1 Definition of terms**

There is no consensus on terminology for use amongst scientists in health and ethnicity research (Bhopal, 2007), however many attempts have been made.

This section addresses some of the issues around defining theoretical terminology in this evolving area of research.

### **Ethnicity definition**

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In their edited selection of theoretical approaches and empirical papers around ethnicity theory and experience, Glazer and Moynihan (1975) described their general theory of ethnicity, as providing:

(Glazer and Moynihan, Eds, 1975; p.3)

Importantly, they distinguished between the 'new' term "ethnicity" as an expansion on the previously dominant term "ethnic group" that had only considered minority and marginal subgroups at the edges of society. "Ethnicity" now also included major elements of a society (Glazer and Moynihan, Eds, 1975). In a more recent discussion of terminology, Nazroo (2001) argued that in order to understand the relationship between ethnicity and health, the term should be theorised adequately, focussing not only on ethnicity as identity, but also as resulting from complex intersections between individual and social agency and structure. The construction of "ethnicity" in research is particularly pertinent, as it influences the work undertaken and the conclusions drawn (Karlsen and Nazroo, in Nazroo, 2006). This, in turn, has consequences for those being studied and others' attitudes towards them – including policy-makers (Karlsen and Nazroo, 2006). However, Bloch and Solomos (2010) conceded that, during the first decade of the 21<sup>st</sup> century, much confusion still surrounded what is meant by the multi-faceted and still-changing phenomenon of "ethnicity". Yet Afshari and Bhopal (2010) have recently noted that the term

"ethnicity" is now preferred over "race" in the current medical scientific literature of Europe and North America. Notwithstanding these concerns and ongoing debates, the following offers a brief overview of the term "ethnicity" as understood in this thesis.

MacLachlan (2006) considered ethnicity to relate to a psychological sense of belonging that is often associated with similar physical appearance or social similarities. The complex concept of ethnicity implies, Bhopal (2004, 2007) argued, one of the following: shared geographical and ancestral origins or social background, shared cultural transitions, cultures and traditions which are distinctive, maintained between generations, lead to a sense of identity "group-ness", a common language or religious tradition. These characteristics are neither fixed nor easily measured, making ethnicity and 'imprecise and fluid' concept. Ethnicity subtly differs from race, nationality, religion and migrant status, but may include facets of these (Bhopal, 2007), confirming Hussein-Gamble et al.'s (2004) observation that the term is not neutral.

Thus, whilst the above demonstrates that there is still little consensus amongst scientists for the correct terminology (Bhopal, 2007), it appears that "ethnicity" is currently the most widely-used; it is the term I use in the present thesis.

### **Culture definition**

Inherent within these definitions of ethnicity, is that of culture. Nazroo (2001) asserted that whilst cultural differences may contribute to variations in health between ethnic groups by influencing health behaviours, values and beliefs, such cultural factors are rarely directly considered in health research. Taking this observation a stage further, Papadopoulos (2006 in Nazroo 2006) argued that persistent failure to consider cultural factors in health research has led to a lack of information for service providers to make informed decisions upon, which could have contributed to health inequalities (discussed in detail shortly). However, Nazroo (2001) urged against imposing rigid cultural categories onto research participants, as culture is fluid and socially embedded alongside other



influences upon health behaviours, such as gender and social class (Nazroo, 2001).

Berry et al. (2006) asserted that numerous definitions of culture exist, which vary in their focus that may be descriptive, historical, normative, structural, genetic or psychological. The latter is of interest here, and may include aspects of adjustment, problem-solving, learning and habits that include shared attitudes, beliefs, categorizations, self-definitions, norms, role definition and values (Berry et al., 2006). These could also serve as examples of implicit culture, whilst explicit culture is considered to be observable in daily customs, acts and products regularly found in a group (Berry et al. (2006). An example of a culturally-situated behaviour that has been observed in the ethnicity and healthcare research literature, is that people from ME groups, and particularly 'Asian' patients, may follow distinctive routes to access treatment (Samanta et al., 2005). The authors attribute this to SA groups' higher usage of complementary and alternative medicine (CAM), and sociocultural perceptions of LTHCs, including RA. These may, in turn, limit SA people's use or acceptance of traditional pathways that access healthcare (Samanta et al., 2005). Clearly these combinations of implicit and explicit culture, as defined above, are of importance in the present study.

However, Cecil Helman's definition takes these concepts a stage further, more accurately conveying the power that culture influences over individual members, and is therefore used here:

(Helman, 2007; p.2)

### 2.2.2 ME Prevalence and experiences of LTHCs

Studying disease patterns by ethnicity can offer insight into disease causation, for example from socio-economic, environmental and cultural perspectives (Siriwardena, 2004). Drawing on data from the UK General Household Survey, Evandrou (2000) found substantial differences between Asian people's health and that of other ethnic groups, whilst differences also exist within and between ME groups. Indian women, for instance are 2.5 times more likely to report having a LTHC than White women. People from South Asian backgrounds are 50% more likely to have premature death from coronary heart disease than the general population (British Heart Foundation/DoH, 2004). In addition to having higher rates of CHD, South Asian people are often diagnosed at a later stage of disease development, making treatment more difficult. Once admitted to hospital with chest pain, South Asian people may experience treatment delays, possibly due to ethnic and cultural differences that may influence presentation and behaviour or the inadequate provision of interpreters (BHF/DoH, 2004). Reasons for such differences and risk factors are discussed later. Similarly, South Asian people in the UK are up to six times more likely than White people to have diabetes (SAHF/Diabetes UK, 2009), which increases the risk of end-stage renal failure and the need for kidney transplant (Randhawa, 2005), and the risk of retinopathy, which is a significant risk factor for blindness (Arai and Harding, 2002). Such serious sequelae of disease underline the necessity for better management, to reduce the burden on the healthcare system, and on individuals and their families.

In addition to increased prevalence of certain LTHCs, evidence suggests that people from ME backgrounds experiences of these conditions is worse than that of the general population. For example, Allison et al. (2002) found that musculoskeletal symptoms were more common among people from BME groups than in the White population in the Northwest of England. Pain in multiple sites was more prevalent among some South Asian people, with 45–64 year old Pakistani and Indian women reporting the highest levels of 'any musculoskeletal pain' and 'pain in most joints' (Allison et al., 2002). Njobvu et al.'s (1999) review confirmed the increased occurrence of reported pain amongst

South Asian groups, but observed that the cause of this remained unclear. Reduced pain thresholds in South Asian populations was one proposed explanation, whilst reported pain may be indicator of mental distress (Njobvu et al., 1999). This underlines the adverse impact of the disease experience amongst South Asian groups.

### **2.2.3 ME Health behaviours**

Differences between ME health behaviours and those of the White population have been identified as areas which could underlie inequalities, and therefore represent potentially useful targets to address in order to reduce inequalities. In this section, I outline differences in risk and prevention behaviours and decision-making amongst divergent groups, and potential reasons for these including health beliefs and medication perceptions.

Cultural differences in risk factors may explain some of these variations on disease prevalence. For example, 52 per cent of Pakistani and Bangladeshi men aged over 60 'currently smoke' cigarettes compared with 19 per cent of older White men and only 10 per cent of older Indian men (Evandrou, 2000). Other risk factors for CHD are common (but variable) in South Asian communities including low rates of exercise across all South Asian groups and a high fat diet with low fruit and vegetables intake among certain groups (BHF/DoH, 2004). Ways in which to address such behaviours amongst ME groups are considered in the 'Patient Education' section.

Minority Ethnic groups have also low uptake rates of some screening and preventative health care strategies (Moudgil and Honeybourne, 1998). For example, one study found that cultural background was a significant predictor of undergoing screening for breast and cervical cancer, even after controlling for potential mediating factors, such as education, family history of breast or cervical cancer, and knowing someone with either disease (Tang et al., 1999). Young Asian women were less likely than young Caucasian women to opt for screening, which could be explained by differences in the cultural barriers to

screening, with Asian women reporting greater sexual modesty and less overall utilisation of Western health care.

Cultural differences in decision-making have been identified as an area that could lead to inequalities. An international study in Singapore and Australasia found that Asian patients' cultural differences may influence attitudes to decision-making in cancer management (Ong, Back, Lu et al. (2002). Western medical systems promote shared decision-making and patient autonomy that differ to traditional Asian cultural and religious attitudes, which could create confusion for patients and clinicians. These traditional beliefs might affect patients' perceptions of diagnosis, symptoms, interventions and concepts of death (Ong et al., 2002). However, the extent to which these findings can be generalised to South Asians in the UK is unclear, in the absence of comparable work. Similarly, Davidhizar and Giger (2004) recognised that the communication of pain during a consultation may be unacceptable within some cultures and that the meaning of pain and its management varies between cultures. Clearly this could affect decision-making in a clinical setting, if, for example, a patient withheld the extent of pain experienced and the clinician decided on a lower dose of analgesic than was actually necessary. The need for cultural awareness training amongst health professionals may help to identify and overcome such issues; I address this shortly.

Understanding patients' health beliefs and perceptions about disease and its treatment, which are influenced by ethnicity, may affect medication adherence and outcome (Kumar et al., 2008). For example, Dickinson and Bhatt (1994) recognized that South Asian women believed that health was a matter of luck and that 'people like them' had no time to think about their health. This may lead them to perceive treatments and self-management as largely irrelevant. Dein (2004) cited international evidence that patients' culture affects how they understand cancer, explain it, their attitudes towards it, and prevention and treatment behaviours. For example, ME people who

considered themselves to be healthy, did not understand the purpose of screening; once this was explained, participants displayed positive attitudes towards cervical cancer screening. Singh (2004) found that ME people did not understand the causes of diabetes, nor the purpose or importance of, for example, when to take medication during the day, or why. These examples provide a potential explanation into reports of poor medication perceptions and adherence amongst people from ME backgrounds, which are considered now.

English-speaking UK students from 'Asian' cultural backgrounds expressed significantly more negative views about medication than those from European backgrounds (Horne et al., 2004). However, this research is limited in its usefulness as it did not use a representative sample, or examine why these differences exist, or what they mean for example, in terms of consultation content, medication prescription or adherence; the ethnic classification is too broad to be very useful. Amongst South Asian musculoskeletal populations, another study found generalised concerns that drugs were overused and harmful, and specific concerns about their own medication (Kumar et al., 2008). In both of these studies, the scales used had not been validated amongst the participant populations, and the potential influence of religion was not considered. Similarly, in their Punjabi and English language interviews with British diabetes patients from Indian and Pakistani backgrounds, Lawton et al. (2005) also found participants were reticent to take medications (*"If you start taking them, you become a patient."* - Indian male; p.2). Instead, participants expressed a preference for traditional adaptation of food to manage symptoms, rather than taking tablets (*"If you keep on taking tablets and not eating strengthening foods like roti, then they will affect you."* - Pakistani female; p.3). Likewise, Dickinson and Bhatt (1994) found male and female South Asian respondents overwhelmingly agreed that diet was central to health.

Thus, the importance of determining the reason for differences in health behaviours is confirmed, so that these might be addressed.

#### 2.2.4 ME Healthcare usage

Many factors may influence ME people's varying usage and experiences of the healthcare system, which in turn influences health outcomes. White people are more likely than Indians in the UK to attend hospital or GP diabetes clinics, although, as previously discussed, South Asian people in the UK have much higher levels of type II diabetes than their White peers (Arai and Harding, 2002), so the reverse may be expected. Hospital admission rates for asthma are also higher for South Asian groups in the UK than for Whites, with no evidence of increased asthma severity (Hussein and Partridge, 2002). Most UK-born South Asian patients knew symptoms, trigger factors, and the reliever/preventer properties of their inhalers, but were dissatisfied with asthma care by their GP (Moudgil and Honeybourne, 1998; Hussein and Partridge, 2002). Another study found South Asian and White patients who had been admitted to hospital coped differently with their asthma. South Asian people were less confident in controlling their asthma, often less confident in their GP, and, in contrast to the above studies, unfamiliar with the concept of preventive medication (Griffiths et al., 2001). The authors advocated interventions that increase South Asian patients' confidence to control asthma, confidence in their GP and understanding of preventive treatment, through the use of community partnerships (Griffiths et al., 2001). Marked differences between reports of South Asian health behaviours underline the need for specific ethnicities to be considered in research, whilst cautioning against over-generalisation. I consider patient education shortly.

Siriwardena (2004) and Evandrou (2000) argued that the consequences of direct and indirect racism may also influence health and experiences of healthcare. As mentioned earlier in this Chapter, The Race Relations (Amendment) Act (Home Office, 2000) legally obligates NHS organisations to address issues of race and ethnicity in their service provision, in order to overcome such issues. Yet Narayanasamy and White (2005) felt that institutional racism still pervaded health care, as the following example demonstrates. Burr (2002) found that mental health care nurses, GPs and

consultants, who worked with South Asian women in a UK urban deprived area, had misperceptions about the women's mental health care requirements. Cultural differences were constructed as fixed categories that 'inferiorised' Britain's South Asian communities. Knowledge was based on stereotypes of Western culture's supposed superiority and Eastern cultures as repressive, inferior and patriarchal. Burr revealed at times disturbing, direct racism ("*they should all go back home... they don't fit in here*" – White female GP; page 841). These attitudes could potentially lead to misdiagnoses and misdirected treatment pathways (Burr, 2002), and stereotyping can lead to erroneous patient care (Siriwardena, 2004); this could constitute indirect racism.

### 2.2.5 Health professional and patient education

In light of the above, the need to educate health care professionals about different cultures is apparent, although how to achieve this without reinforcing cultural stereotypes is a complex challenge (Narayanasamy, and White, 2005; Stuart, 2004). Tripp-Reimer et al. (2001) suggest that rather than viewing patients' culture as a barrier to care, health professionals working with diverse populations should be trained to view the barriers as arising from biomedical culture. Cultural competence (CC) training has been proposed for health workers, including for medical students (Godkin and Savageau, 2001), nurses (Wilson, 2004), counselling psychologists (Vera and Speight, 2003) and care workers (Papadopoulos et al., 2004).

In addition to training health professionals, the health education of ME individuals has also be considered as a method of overcoming health inequalities. However, amongst ME groups, this may not necessarily be in the format of formal education. Kinship networks exist within heterogeneous South Asian groups, which may represent informal education systems (Randhawa, 2005). For example *biraderi* (brotherhood) is central in Pakistani and Kashmiri communities. This social framework controls, for example, the widely held concepts of honour and shame within South Asian communities, with

considerable implications for HIV/AIDS transmission (Weston, 2003). Clearly, these social structures have potential for the dissemination of structured health messages that may have a snowball effect. Citing transplantation studies in UK South Asian populations, Randhawa (2005) found that health information imparted in a culturally sensitive way to key Pakistani families travelled quickly to families elsewhere in England through pre-existing kinship networks. This was more effective than the South Asian language DoH literature and videos. Other South Asian subgroups have different kinship patterns, formed through caste and religious affiliations (Randhawa, 2005). These studies again demonstrate the vital importance of accessing voluntary, community and religious groups for face-to-face dialogue with 'ethnically directed' health messages.

Considering formal health education interventions, research undertaken with ME groups suggests their health literacy and inequitable experience of health and healthcare, may be partly attributable to a lack of culturally appropriate educational resources. Numerous studies have shown that educating patients to increase their knowledge and improves health (Dein, 2004). However many ME patients do not speak English and are illiterate (in any language) and therefore require careful consideration as how best to educate. Clearly dependence on English, text-based, materials will be inadequate - indeed, a listening-based relationship with a person who understands, is valued over written materials in South Asian cultures (Adebajo et al., 2004). Similarly, resources that are tailored to the cultural needs of target communities, for example to consider ethnicity-specific health beliefs (such as those outlined above), are more likely to have 'real practical value' (Samanta et al., 2009; Brach and Fraser, 2001). The success of culturally competent health education, to improve ME health literacy, is discussed now.

In Hawthorne's (2001) educational intervention, literate British Pakistani women who were living with Type 2 diabetes in London, improved both their knowledge and glycaemic control levels. Practical tuition was supported



pictorially by flashcards, and administered by a female British Pakistani linkworker. In a prospective cohort study, McAvoy and Raza (1991) found that health education interventions increased uptake of cervical cytology among Asian women in Leicester. Home visits were most effective, especially when the women were also shown a video (compared to being shown translated written materials). Translated written materials sent by post without a home visit were ineffective (McAvoy and Raza, 1991). In Randhawa's (2005) study, cited earlier in this review, the translated written materials and video about organ donation were not supported by home visits, but by the mass media, which could explain their ineffectiveness.

However, it cannot be assumed that ME health beliefs always differ from the majority White population. For example, Dein (2004) found a clear lack of knowledge about cancer in non-English speakers in the UK, demonstrating a need for education about symptoms and medication. This shows that South Asian people's non-participation in for example, screening tests and late presentation for professional help, may NOT reflect cultural or fatalistic beliefs (Dein, 2004). Similarly (and in line with Horne et al., 2004, above), Greenhalgh, Collard and Begum (2005) asserted that British Indian and British Pakistani patients did not want to take more tablets than necessary and discontinued their tablets if they had major side effects. In this respect they were more similar than different to the indigenous British population, suggesting that a patient's health literacy may therefore be more important than "culture" in explaining health beliefs (Greenhalgh et al., 2005).

The potential utility of lay-led, group based education amongst South Asian groups will now be considered. Greenhalgh et al. (2005) qualitatively examined non-English speaking British Bangladeshis who attended ongoing diabetes discussion groups led by a trained, bilingual, health advocate. Participants achieved positive outcomes not purely through knowledge acquisition (although this was important) but by repeatedly discussing their new

knowledge, reframing and challenging it within the group, which only then made it meaningful to them, and prompted action (Greenhalgh et al., 2005). In another diabetes educational intervention, in the Foleshill area of Coventry, knowledge was essential to successful self-management (Singh, 2004). Temple staff and members were trained, with audio- and video-taped materials preferred over written guidance. Simple medical explanations about diabetes and awareness-raising of local services, were reinforced by a follow-up telephone call, then condition- and ethnicity-specific group-work and monthly drop-in sessions. At the end of each group-work session, discussion topics for the next session were decided by attendees (Singh, 2004). This would have enhanced attendees' sense of empowerment and self-determination over their progress, which, speculatively, may have improved their self-efficacy and potentially contributed to the assumed improvement in self-management and diabetes symptoms.

### **Summary**

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People from ME backgrounds who live in the UK experience inequities in health status. Stereotyping by healthcare professionals may exacerbate distinct health beliefs, behaviours and knowledge-levels of diverse South Asian groups, which could be overcome by sensitive training. Community-based group interventions targeting specific South Asian groups are required, supported by culturally appropriate educational materials.

### **2.3 LTHC Self-management interventions**

At the beginning of this Chapter, international and national policy literature was outlined, which confirmed the important effects that educational interventions supporting LTHC self-management can have on reducing the burden of disease; the need to implement such interventions with specific reference to ME groups was highlighted. Next, examples of ME health inequalities, and the potential utility of health education interventions to overcome these inequalities

were highlighted. This section first describes the background to self-management education and the content of EPP. I then outline the theoretical framework for EPP, before examining the evidence around the self-management interventions that have directly led to the development of the EPP, which is the focus of the present Study. Finally, a critique of self-management interventions is offered.

Self-management of health conditions is a broad subject that has attracted much international research attention. Whilst other structured group educational interventions exist (e.g. the diabetes education and self management for ongoing and newly diagnosed programme - DESMOND), they are beyond the scope of the present thesis, which focuses on EPP.

### **2.3.1 Definition of terms**

#### **Self-management definition**

The aim of self-management is to minimise the impact that a LTHC has on physical well-being and functioning, whilst addressing the psychological consequences of the condition (Lorig and Holman, 2003). Self-management activities are usually undertaken by the patient, outside the healthcare setting, in collaboration with healthcare professionals. Activities include treating the condition, physical and psycho-social symptom-management, and effecting lifestyle changes (Glasgow et al., 2003). Thus it is apparent that LTHCs have physical, psychological and social costs to the individuals with the conditions, which cannot be dealt with separately. However Clark et al. (in Barlow Wright and Sheasby, 2002) also considered the circumstances that are required in order to achieve self-management, acknowledging that financial and social constraints may affect this. They further recognised that individuals need the knowledge and skills about the condition, treatment options and of the range of self-management strategies that are available. The definition adopted in this thesis, which embraces these features of self-management, therefore refers to:

(Barlow, Wright, and Sheasby, 2002, pg.178)

### **Self-management education definition**

Many health education interventions address medical or behavioural management tasks, but a minority also consider the importance of role management and/or emotional management (Lorig and Holman, (2003). 'True' self-management educational interventions need to fulfil several criteria; without every component's inclusion Lorig (1996) advocates that the terms 'self-help' or 'self-care' are more appropriate.

Lorig's (1996) self-management education criteria are:

- Content presentation focused on patient needs; and
- Practice and feedback in new skills, including problem-solving and decision-making; and
- Attention to emotional and role management, in addition to medical management; and
- Use of techniques to increase patients' confidence in their ability to manage their conditions; and
- Emphasis on patients' active role in the doctor-patient relationship.

Kennedy et al. (2007) note that EPP is informed by principles of social inclusion and empowerment; these are not enacted, however, as reflected by low BME attendance.

### 2.3.2 Theoretical framework for self-management education

With no known cure for many LTHCs at present, the development of new drugs and surgical techniques is often the focus of disease management. Whilst promising, these advancements fail to address the highly complex behavioural, cognitive, physical, emotional, and psychological processes involved in the pathogenesis and progression of LTHCs (Marks and Allegrante, 2005a). Self-management education emerged in recognition that tertiary care for patients dealing with these consequences of living with LTHCs often fell "through the cracks" (Lorig, 1996). The success of the ASMP (Griffiths, 2007), detailed shortly, led to the development of CDSMC, and is now known as EPP in the UK. The intervention follows the 'Stanford Model' of patient self-management education, developed by Prof Kate Lorig and colleagues at Stanford University's Patient Education Research Center. The content and format of the highly structured ASMP and EPP are essentially the same, differing only in respect of the provision of arthritis-specific information in the former.

The EPP is typically delivered by pairs of trained, accredited lay-tutors, who themselves live with a LTHC, thus affording opportunities for modelling self-management behaviours by peer-educators. This psycho-educational course is delivered from a scripted manual to ensure a consistent standard of delivery across time and groups (Barlow, 2009). Course attendance is usually by self-selection, removing the need for medical referral; this decision to attend has been considered the first step towards becoming a more successful self-manager (Wright et al., 2003). Courses are delivered to groups of around 8-15 people in non-clinical settings such as community centres (Barlow, 2009). Comprising six, weekly sessions, each lasting approximately 2½ hours, the content of these multi-component courses use is summarised in Box 2.1, overleaf.

Learning formats include 'lecturettes', role-play, problem-solving and contracting (i.e. goal setting, which I return to shortly) (Barlow, 2009), with these participative techniques fostering self-management skills (Griffiths, 2007). By imparting new skills or knowledge to enable attendees to manage symptoms or

### **Content of standard six week chronic disease self management course**

- **Session 1** Course overview; acute and chronic conditions compared; cognitive symptom management; better breathing; introduction to action plans
- **Session 2** Feedback; dealing with anger, fear and frustration; introduction to exercise; making an action plan
- **Session 3** Feedback; distraction; muscle relaxation; fatigue management; monitoring exercise; making an action plan
- **Session 4** Feedback; making an action plan; healthy eating; communication skills; problem solving
- **Session 5** Feedback; making an action plan; use of medication; depression management; self talk; treatment decisions; guided imagery
- **Session 6** Feedback; informing the healthcare team; working with your healthcare professional; looking forward.

**From Griffiths (2007)**

### **Box 2.1: Weekly content of EPP**

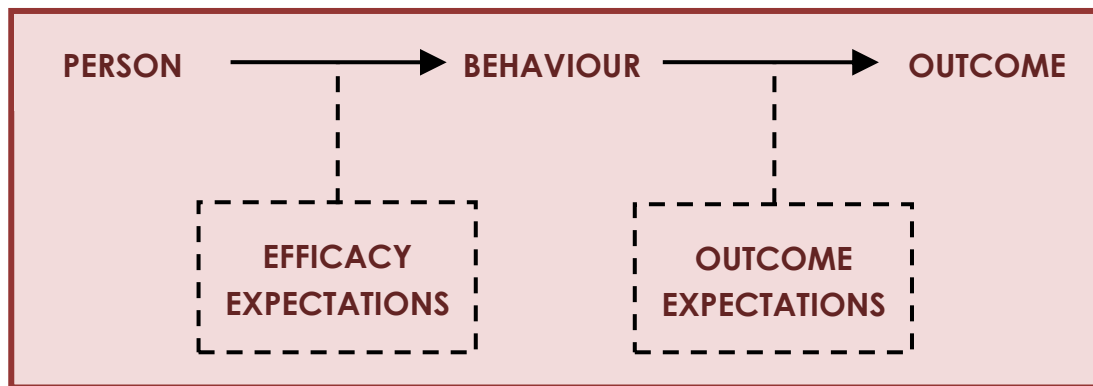
to cope with the limitations of their LTHC, courses aim to modify attendees' behaviour by undertaking these activities, thus minimising the impact of the LTHC and preventing deterioration (Rijken et al., 2008).

### **Theoretical framework**

This intervention is grounded in the self-efficacy component of Bandura's Social Cognitive Theory of behaviour (Bandura, 1977, 1997). The key predictors of successful behaviour change, in this psychological theory, are:

- self-efficacy in the ability to carry out an action (efficacy expectations) and
- expectation that a particular goal will be achieved (outcome expectations).

This is shown diagrammatically in **Figure 2.1**:



*Adapted from Bandura (1977); pg.193*

**Figure 2.1: Diagrammatic representation of the difference between efficacy expectations and outcome expectations.**

Self-efficacy is potentially modifiable and evidence demonstrates that it impacts upon health status, motivation levels, and medication adherence (Marks et al., 2005a), and is therefore considered to be a prerequisite for behaviour change. Improving attendees' perceived self-efficacy is a key component of self-management interventions (Lorig et al. 2001), including EPP. Bandura (1997) defines self-efficacy as the:

(Bandura, 1997; pg.3)

Enhancing attendees' self-efficacy takes several formats on EPP. For example, in the problem-solving section, attendees' are encouraged to identify barriers to achieving a desired goal, by breaking it down into the necessary steps that

are required to achieve the goal. By identifying and removing barriers incrementally, by setting small, achievable targets for themselves in each week's action plan, attendees' self-efficacy is enhanced, through a process known as skills mastery. Action plans have to be reasonable, action-specific, and state What?, How Much?, When? and How Often? the action will be undertaken (Kennedy et al., 2007).

The theory further asserts that in addition to outcome and efficacy expectations, behaviour is influenced by observational learning and social influences including social norms, social support or pressure, and the behaviours of others (modelling) (Rijken et al., 2008). The action plan is set in front of the group by each attendee every week, and the outcome is reported back to the group the following week; this peer pressure motivates attendees to achieve their action plan and so enhances their self-efficacy. However, success cannot be guaranteed: group social support is encouraged in the event of non-completion and learning how others' overcome difficulties in achieving their action plan (peer modelling). Thus, the small incremental achievements of the weekly action plan contribute to attaining the eventual goal. Self-efficacy was recognised as having a key role in the likelihood of health behaviour changes being adopted and maintained and was associated with improved affect, heightened motivation, better function, treatment adherence and improved clinical and social outcomes, in two extensive literature reviews (Marks et al. 2005a, 2005b).

This highlights the considerable effort and commitment that psycho-educational interventions demand from attendees (Barlow, 2002). Indeed, Rogers (2009) advocated increasing research focus on the social and domestic contexts required to embed new techniques in the routine elements of self-management. Thus, the importance of understanding the psycho-social context in which changes occur is confirmed. Similarly, Taylor and Bury (2007) asserted that awareness of these cognitive/psychological factors involved in



self-management behaviours "should not draw attention away from the social determinants and contexts of health" (p.27). This thesis addresses these factors.

### **2.3.3 Effectiveness data for self-management interventions**

This section first highlights a number of reviews that have taken a broad-brush approach, which included evidence from the Arthritis Self-management Programme (ASMP) and Chronic Disease Self-management Course (CDSMC), and, also, other courses. Then I consider international and national work on ASMP and CDSMC, on which EPP is based. This is followed by UK effectiveness trials on EPP itself and an example of its use with South Asian groups. Examples of its development amongst ME groups are given throughout.

#### **Generic self-management education intervention reviews**

Barlow et al. (2002) reviewed 145 books, papers and theses, to identify approaches to self-management, and to consider the effectiveness of such approaches. Approaches included group/individual, lay-/ health professional led, community/clinic delivery of the intervention; few differences were found, apart from the anticipated increased cost associated with individual interventions. They concluded from several Randomised Control Trial (RCT)s that self-management programmes are effective in increasing knowledge, symptom management, use of self-management behaviours and self-efficacy, and promote beneficial medical outcomes (Barlow et al., 2002). However, not all self-management courses targeted all outcomes, and multi-component courses did not show improvements on all outcomes. The authors highlighted that whilst these variations in design could be considered evidence that different patients' groups' needs were being addressed, the resultant variability in evaluation methods, measurement tools, render meta-analyses of little value in determining effectiveness (Barlow et al., 2002).

Warsi et al. (2004) systematically reviewed 71 self-management education trials. Diabetic attendees demonstrated improvements in haemoglobin levels and

systolic blood pressure levels, and asthmatic attendees had fewer attacks. Whilst statistically significant differences were identified between intervention and control groups for pain and function in OA self-management education programmes, the pooled effects were not, however, associated with statistically significant effects.

Similarly, in their meta-analysis of 53 RCTs on self-management interventions focusing on elderly patients with diabetes, hypertension or OA, Chodosh et al. (2005) found statistically significant and clinically important evidence that self-management programmes improved some physiological outcomes. Blood glucose control improved amongst diabetes patients, and blood pressure reduced for hypertension patients. The statistically significant effects that were seen on the physiological outcomes of pain and function amongst arthritis patients were, however, dismissed as 'clinically trivial'. This finding demonstrates Chodosh and colleagues' fundamental misunderstanding of the importance of physical well-being to patients. Finally, not all of the studies in the meta-analysis incorporated a psychological element, and are not, therefore, directly comparable with, for example, CDSMC, with its psychological theoretical framework (e.g. Barlow et al., 2002).

In their Cochrane review of 17 RCTs, Foster et al. (2007) compared structured lay-led self-management education programmes for LTHCs against no intervention or clinician-led programmes. They concluded that lay-led programmes might lead to small, short-term improvements in participants' self-efficacy, self-rated health, cognitive symptom management, and frequency of aerobic exercise. However, they did not find evidence that such programmes improved psychological health, symptoms or health-related quality of life, or that they significantly altered healthcare use (Foster et al., 2007). Yet seven studies reported small, statistically significant improvement in communication with healthcare professionals amongst the intervention groups, suggesting that patients' satisfaction with GP or physician visits had improved. There were insufficient data to determine whether disease-specific interventions were more or less effective than generic interventions, or to ascertain the effectiveness of

programmes across ethnic groups. Similarly, it was unclear what the most important features of education programmes were (e.g. duration, format, content or context of the self-management training, or on aspects of tutors' training and accreditation) (Foster et al., 2007). The authors' recommendations include addressing the under-representation of BME people on self-management interventions, and the use of qualitative studies to explore how participants experience the intervention, "e.g. *what aspect of the courses do participants like/dislike, why do people drop out, why is attendance low?*" (Foster et al., 2007; pg.19). This thesis directly addresses these recommendations. In a very similar review, Newbould et al. (2006) also acknowledged the potential short-term benefits of enhanced self-management from the provision of lay-led education programmes. The observation was again made that particular communities' requirements required assessing so that appropriate local responses could be arranged. However, their conclusions were much less positive than Foster et al. (2007); I return to this at the end of this Chapter.

In another review, of 63 asthma, diabetes and arthritis studies, Newman et al. (2004) noted, as in the previous reviews, that interventions' content and studies' primary outcome measures varied between the disease groups. For example, asthma interventions focussed on symptom-monitoring and medication adherence, with few considering emotional management; improving pain and physical and psychological functioning were prominent amongst arthritis interventions. Similarly, individual and group settings were included, whilst other interventions were internet-based or postal; this again makes direct comparisons problematic. Newman et al. found insufficient evidence to determine whether lay- or healthcare professional-led interventions were more effective. Notwithstanding these methodological concerns, amongst the arthritis interventions, approximately 40% showed some improvement in self-reported symptoms and disability measures (Newman et al., 2004). Behaviour-change was identified as the most successful outcome across the disease groups. The authors concluded that uptake of self-management interventions may be influenced by how and when they are offered to patients. Importantly,

they noted that as with medication, one programme might not suit all patients; whilst the last two points were not made with any reference to ME groups, this may be particularly pertinent.

In the final review to be considered here, Lorig and Holman (2003) described the results of RCTs based on the Stanford Model self-management programmes (i.e. CDSMC, ASMP). Positive effects were found on the frequency of behaviours including exercising and symptom management and pain reduction was reported in all studies with patients with arthritis and back pain; disability was often reduced. As with Foster et al.'s (2007) review, above, participants reported improved communication with their physicians. Lorig and Holman (2003) noted significant reductions in healthcare utilisation in two studies. However, the authors remained uncertain as to the precise mechanism that achieved the reported self-management effects; they argued that self-efficacy likely had a central role.

## **ASMP**

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### **International evidence**

Lorig and Holman (1993) conducted four studies, designed following a review of their previous 12 years' work, and concluded that collectively, the evidence demonstrated ASMP improved self-management behaviours, self-efficacy, and aspects of health status. Their findings suggested that changes in perceived self-efficacy affected health status more than behaviour changes, confirming the fundamental importance of this psychological construct. In addition to clinical benefits, the authors also reported cost savings (Lorig and Holman, 1993). Improvements in pain and depression - despite an increase in disability - lasted for as long as four years without formal reinforcement (Lorig, Mazonson and Holman, 1993). However, Bury et al. (2005) criticised that study for being methodologically weak, as it used retrospective comparison of unmatched groups.

In their meta-analysis of 17 arthritis self-management interventions, Warsi et al. (2003) concluded that arthritis self-management education programmes result

in small but significant reductions in pain and disability, with no significant evidence of publication bias toward studies finding reductions in pain or disability. Similarly, Riemsma et al.'s (2003) Cochrane review of patient education for people with RA (not limited to ASMP, but also included psycho-behavioural methods, exercise, biofeedback and psychosocial support) found statistically significant short-term improvements in functional status, the number of affected joints, self-reported health and overall psychological status, but not on pain, anxiety and depression levels. Whilst these findings cannot be applied directly to ASMP, they suggest the overall benefits that arthritis patient education may offer.

In the US, Hispanic populations experience health inequalities, and arthritis is the leading cause of disability in these groups (Lorig, González and Ritter, 1999). The ASMP was translated into Spanish in order to address this; recruitment, delivery and course materials are all in Spanish. The results of a four- and twelve-month follow-up of an RCT of the Spanish ASMP were encouraging. The intervention group had statistically significant improvements in exercise, disability, pain, and self-efficacy scores compared with baseline. Self-efficacy predicted health status at twelve-month follow-up, demonstrating the importance of this construct amongst Hispanic communities. Improvements in exercise, general health, disability, pain, self-efficacy, and depression were also detected at twelve-month follow-up amongst controls (Lorig et al., 1999).

## **UK evidence**

Effectiveness studies have also been conducted in the UK. For example, Barlow, Turner and Wright (2000) conducted an RCT to examine the effectiveness of ASMP. Four months after completing the course, attendees had significant improvements in self-efficacy, symptom management and reduced pain and significantly greater health behaviour performance in communicating with health-care professionals, dietary habit, exercise and relaxation compared to a waiting-list Control Group. The Intervention Group

were also significantly less depressed and had greater positive mood. Physical functioning, pain and GP visits remained stable at four months. At 12-month follow-up, the intervention group had maintained these improvements, moreover statistically significant improvements on pain and a decrease in visits to GPs were identified. Apart from a small improvement on physical functioning at 12-months among the intervention group with OA, results were independent of type of arthritis (Wright, Barlow and Turner, 2003). This demonstrates ASMP's potential across different types of arthritis.

In their UK RCT of ASMP among people with OA, Buszewicz et al. (2006) performed twelve-month follow-ups with attendees. Attendance reduced anxiety and increased self-efficacy for managing pain and other arthritis related symptoms. However no significant effect was detected on pain or physical functioning scores, and ASMP attendance did not reduce the number of GP consultations (Buszewicz et al., 2006). This may be because the intervention encouraged participants to seek advice from primary care professionals; satisfaction was not measured. The authors conclude that ASMP can enhance self-management techniques and improve physical and psychological health outcomes. Yet with a 100% White sample in the intervention group, and <1% Black African/Caribbean controls, the trial evidently failed to attract BME groups – a well-recognised issue discussed elsewhere in this thesis. However, the inclusion in this data is useful nonetheless.

Yet ASMP evaluations had been criticised for being too short-term in their period of follow-up; this was addressed recently by Barlow et al.'s (2009) eight-year ASMP follow-up study. Patients' scores from the original RCT (Barlow, et al., 2000, above) were compared with data collected eight years after participants had originally attended ASMP. Observed improvements between baseline and four-month follow-up were maintained at eight years for self-efficacy, health status and use of self-management behaviours. For example, anxiety and depression scores were maintained over the three time points, and a statistically significant increase in walking was found. Whilst there were no

significant changes in the number of visits to GP or health professionals, this is noteworthy considering a decline in physical functioning was detected. The absence of a control group means findings are not causally attributed to ASMP; many other things could have influenced the participants' health behaviours in intervening years, including receiving healthcare. Furthermore, the 98% White sample shows bias in ethnicity that unavoidably reflected the initial sample.

Qualitative research has also shown that the ASMP provides participants with 'tools' to change the way they manage their condition, which may, for example, have important implications for health-related quality of life and ability to maintain employment or independent living (Turner, Barlow and Williams, 2000). These findings suggested that the Programme effectively promoted improvements in attendees' perceptions of control, health behaviours and health status. In their eight-year follow-up of ASMP, Barlow et al. (2009) also conducted interviews with five participants with high self-efficacy scores and five with low scores. Some low scoring participants expressed disappointment that ASMP had not provided the expected 'quick fix' to their condition, had not learned new techniques, and that the positive focus invalidated the severity of problems that they experienced. The authors suggest that addressing pre-course expectations may address this, or that these patients may benefit from specific psychological support (Barlow et al., 2009). Yet both low and high self-efficacy participants had appreciated meeting similar others and the opportunities that this afforded for social comparison, and were using self-management techniques such as goal-setting, feeling more in control of their lives (Barlow et al., 2009).

Together, these studies suggest that both physical and psychological aspects of living with arthritis can be addressed by self-management interventions. Inconsistencies in findings may be attributable to variations in study design.

### International evidence

Whilst ASMP is condition-specific, the condition-generic CDSMC allows people with any LTHC (including arthritis) to learn self-management techniques. The underlying premise of the generic course is that people with LTHCs have similar concerns and problems (e.g. anxiety, fatigue) (Lorig and Holman, 2003), and, as with ASMP, this affords opportunities for peer-support in a structured learning environment. With the removal of arthritis-specific information, CDSMC is otherwise no different from ASMP in concept, content or delivery. Following the recognition of ASMP in the US and UK, CDSMC was developed and has been the subject of a number of RCTs around the world amongst divergent populations; these will be discussed now.

Lorig, Sobel, Stewart et al. (1999) performed a six month RCT of CDSMC in the USA. Results showed that Course participants were exercising more, better managing their cognitive symptoms, reported improved communication with health care professionals, and self-reported improvements in health, health distress, fatigue, disability, and social/role activities limitations. They also had fewer hospitalisations and days in hospital than the waiting list control group (Lorig et al., 1999). Similarly, Lorig, Ritter, Stewart et al. (2001) conducted longitudinal community-based research, one and two years after participants had attended CDSMC. Emergency hospital admissions, outpatient visits and self-rated health distress were all significantly reduced, whilst self-efficacy significantly improved. However, given the differences between the structures of US and UK health systems, it appears unwarranted to draw conclusions that CDSMC may represent a method to reduce healthcare costs here.

International research also confirms the effectiveness of the CDSMC for use in ME groups. For example, Lorig, Ritter and González (2003) evaluated a Spanish-language course for use with US Hispanics. Compared with controls, intervention participants had significantly improved health status, health



behaviour, self-efficacy, and fewer emergency hospital visits, at four-month follow-up. These improvements were maintained and remained significantly different from baseline, at 12-month follow-up. The inclusion of self-efficacy as an improved outcome is noteworthy, and indicates that this construct exists outside English-speaking communities; this is believed to be the first time that this was found in the self-management context.

Australian research investigated the extent to which the Course required modification so that concepts around self-management could be made more relevant to Vietnamese, Greek, Chinese and Italian communities with various LTHCs (Walker et al., 2005), if appropriate. Considerable disparity was identified between healthcare professionals' perceptions of patients' beliefs and expectations, and patients' actual beliefs and expectations. Conceptual aspects of the course require little modification, with myths around the importance of fatalism dispelled. Yet high levels of illiteracy in participants' own language and in English require the course materials to be made accessible and equitable for non-English speakers (Walker et al., 2005).

The same team then conducted an RCT on the four versions of CDSMC in Chinese, Italian, Greek or Vietnamese (Swerissen et al., 2006). Pairs of trained bi-lingual tutors delivered CDSMC in participants' first language, following a rigorous process of translation, pilot testing and back translation on the Leaders Manual. Participants were recruited using numerous media, including public service announcements on local ethnic language radio programmes, self-referral from posters and brochures left in GP and community service waiting rooms, and community 'ethno-specific' newspapers. The study instruments were translated into the four community languages by Professional Level accredited translators. The outcomes assessed were health status, health behaviours, self-efficacy and health service utilisation. Community meetings, home visits, telephone interviews and mail outs were used to overcome issues around low literacy and to ensure high response rates. At six-month follow-up, intervention group participants had significantly higher scores than controls on

energy, exercise, symptom management, self-efficacy, general health, pain, fatigue and health distress (Swerissen et al., 2006). There were no significant effects for health services utilisation, whilst language Interactions were observed across groups, with the Vietnamese and Chinese speaking participants gaining greater benefit. Italian attendees had higher levels of health distress, which warrants further investigation. The authors' earlier study had observed that high levels of illiteracy in participants' own language and in English required that course materials were accessible and equitable (Walker et al., 2005), yet Swerissen et al. (2006) did not comment if/how this was done; furthermore there was no mention of translation for attendees' course manual for those who could read in their first language.

The potential importance of self-management for people with LTHCs was recognised as a necessary part of treatment in Shanghai, China where Dongbo et al. (2003), examined CDSMC's feasibility, benefits, and cultural sensitivity. Whilst the implementation of a Chinese CDSMC with Chinese people in China is patently not a ME application of the intervention, the potential for cross-cultural benefits of learning from both process and outcomes warrants its inclusion here. Cultural tailoring included deleting the topic *"making your wishes known: advance directives for health care"*, because Chinese patients would feel uncomfortable discussing issues around death. Culturally familiar exercises (shadowboxing, Chinese relaxation/*Taiji*) replaced the standard content. The tutors' delivery manual and the attendees' coursebook were translated into common Chinese words and sentences, refined as necessary, and then piloted for content and delivery process (Dongbo et al., 2003). Evaluation was by pre-tested (details not given) self-administered Chinese version of the questionnaire on chronic disease self-management study measures, originally developed by Lorig et al. (1996). Attendees had statistically significant improvements in weekly minutes of aerobic exercise, practice of cognitive symptom management, self-efficacy both to manage symptoms and disease in general, compared with controls at six-month follow-up. They also had significant improvements in self-rated health, health distress, fatigue, shortness of breath, pain, disability, depression, and social and role activity limitations,

and significantly fewer hospitalisations. The authors concluded that the CDSMC was culturally acceptable to Chinese patients, affording significant improvements in eight indices of health status six-months post-course (Dongbo et al., 2003). This dismisses the perception that people from non-Western cultures (i.e. from 'collectivist' cultures) may not find the fundamental concept of self-management itself, to be culturally acceptable.

## **CDSMC/EPP**

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### **UK evidence**

Kennedy, Gately, Rogers et al. (2004) undertook a national evaluation of the EPP pilot process across the UK. Their principal aims included highlighting major achievements and identifying barriers to establishing functional EPPs in the 62 NHS pilot sites. Qualitative evidence showed that those with direct contact with recruiting patients and delivering courses (such as tutors) experienced EPP as an effective and innovative means of managing LTHCs. Barriers to successful implementation of EPP included insufficient time available to busy NHS managers with lead roles in the pilot scheme, and ambivalence from health care professionals. By increasing the business profile of the pilot in PCTs, these EPP leads could spend more time engaging health professionals in the benefits of introducing the Programme. Ensuring equity of access to people in deprived neighbourhoods and those from minority ethnic backgrounds was identified by many Trusts as areas requiring attention (Kennedy et al., 2004). At the time of the study, EPP was only deliverable in English, which excluded many potential attendees, although translation of course materials and productions of an audio-taped version had begun.

Importantly, Kennedy et al. (2004) reported mixed results but acknowledged that EPP clearly has major impact on many people. The authors question the NHS has the capacity to deliver EPP nationally, how it will become routinely 'prescribed', whether it will still be as successful if attendance is no longer voluntary and want effectiveness data for lifelong conditions and what

reinforcement is necessary to maintain changes. However, the DoH (2006) white paper detailed in the Policy literature review (Chapter 3.1) largely addresses these concerns. Furthermore, Mulligan, Newman, Taal et al. (2005) acknowledge that whilst RCTs are the gold standard in medical research, they are not necessarily best for self-management intervention studies. For example, variables that are potentially important but are not routinely examined in RCTs - including culture - need to be measured, as they may have a moderating effect on the intervention.

In their RCT of EPP with waiting list control in community settings, Kennedy et al. (2007) found that, compared with the control group, attendees had significantly increased self-efficacy, energy and health-related quality of life at 6-month follow-up. The EPP did not affect routine health-services utilisation; however this finding does not consider potential improvements in satisfaction with services, for example arising from improved communication with healthcare professionals. A cost-effectiveness analysis showed that attendance resulted in a reduced cost of £27, which was considered cost effective "at conventional levels of a decision makers' willingness to pay" (pg.258). Whilst no specific inclusion or exclusion criteria were used beyond having a self-defined LTHC, 95% of attendees were White (other ethnicities not detailed); although participants were evidently not deliberately excluded on grounds of English language ability, it appears likely that people from BME backgrounds were under-represented on this RCT.

One RCT has considered ME people in the UK, In an ethnicity-specific RCT with 300 Sylheti-speaking Bangladeshis in Tower Hamlets (Griffiths, Motlib, Azad et al., 2005) aimed to establish the effectiveness of EPP among Bangladeshis living in Tower Hamlets and to understand the structural and cultural barriers to success of EPP. All participants were interviewed at the start of project, and then randomised into either the waiting list control group, or the 'immediate education' group. The intervention was attendance on a three hours/week for six weeks, EPP course adapted into the Sylheti dialect and Islamic culture. Courses were lay-led by trained and accredited Bangladeshi tutors with a LTHC,

with men and women attending separate courses. Participants attending three or more sessions showed greater improvements than the control group in self-efficacy, cognitive symptom management and had improved depression scores at four months, but no change in health service usage. These findings support previous research around EPP. Yet the authors cited unpublished qualitative analysis of interviews with non-attenders that revealed participants' faith was a potential barrier to successful self-management. For example, participants were quoted as saying that doctors were not responsible for their future, but Allah was, and that illness and hardship were tests from Allah, or punishment for sins. Griffiths et al. recommended future research addresses these factors, which the present project will. It appears that the tailoring around Islamic culture had not fully addressed concerns of attendees. Spirituality and religiosity will be examined in detail in Chapter Six. Whilst detail is not provided about how measures were translated and validated for use amongst this population, this study currently represents the only RCT of EPP for use amongst South Asian groups.

#### **2.3.4 Discussion of ASMP/EPP**

This section has shown, using evidence from different countries and with different patient groups, that there is evidence that self-management educational interventions are effective at increasing the use of self-management behaviours including cognitive and physical symptom management, and improving attendees' self-efficacy, psychological and health status. However, EPP has been subjected to much criticism in terms of the validity of the evidence-base, philosophical considerations and pragmatic concerns about the equity of its implementation. These are addressed now.

#### **Methodological considerations**

In order to provide a balanced understanding of the backdrop to the current research, some general criticisms that have been made about EPP will be considered, before I address more specific methodological issues. Bury,

Newbould and Taylor's (2005) Rapid Review of the evidence base gave a cautious welcome to lay-led self-management interventions. However, their conclusions that *"the fact that even well-intended innovations can sometimes cause harm ... it is reasonable to warn that there is a future risk of such hazards materialising"* (pg.19) is particularly noteworthy. This statement directly contradicts the cited studies that state no harm occurred to any participant. The same team then questioned the validity of EPP's implementation based on the extant evidence-base. Indeed, they asserted *"the possibility that advocates of public service improvements have on occasion been tempted to overstate the evidence for the relative and absolute effectiveness of lay-led self-management programmes"* (Newbould, Taylor and Bury, 2006). However, these forthright allegations have again been dismissed. For example, Rogers (2006) suggested that positively framing CDSMC's potential benefits may simply have emerged from *"the US enthusiasm for generating a 'can do' attitude"* (pg. 263). Likewise, Newbould et al.'s criticism of the structure and process of the course as telling a person what they 'should' do is unsubstantiated and *"The opposite is in fact the case."* (Battersby, 2006; pg.266). Similarly, Greenhalgh's (2009) assertion that the success of self-management is defined by compliance with management plan negates the importance that the patient identified and negotiates the goals, and steps towards them. Finally, whilst acknowledging the benefits of EPP, Griffiths et al. (2007) propose that the 'considerable hyperbole' around it is partly due to powerful patient accounts. This effectively highlights another strength of the course that is rarely mentioned in RCTs and reviews, but frequently appears in qualitative work: patients love it (e.g. Barlow, Williams and Wright, 1999).

Looking at more specific methodological issues, the need to adopt standardised methodologies in RCTs of self-management interventions would remove suggestions of bias. For example, Buszweicz et al., Chodosh et al. (2006) and Warsi et al. noted that trial methods varied substantially and were suboptimal in, for instance, what were reported as primary/secondary outcome measures; future trials should adhere to a standard methodology. Buszweicz and colleagues also commented that the RCTs did not account for entry

criteria, which can dramatically affect outcomes; a point that Kate Lorig made recently:

(Jones, 2010; pg.xvi)

Thus, in the analysis of multi-component courses, modest effect sizes are the norm – this only becomes problematic when they are introduced inappropriately into meta-analyses; a point made by Barlow et al. (2002). Swerissen et al. (2006) highlighted an issue around self-selected community recruitment, the preferred method in CDSMC. The most motivated people enrol, which skews the results; they suggest that recruitment should be systematised as part of the routine referral process for healthcare delivery. I return to issues around healthcare professionals' perceptions of EPP and equity of access shortly.

Similarly, future studies linking specific components of the programmes to outcomes will reveal the most important features, a noteworthy shortcoming in the current evidence base. For example, Taylor et al. (2005) suggest that the duration, format, content, context of the training, or the tutors may influence outcomes. Once identified, these elements can be further developed in future self-management programmes (Lorig and Holman, 2003; Rijken et al., 2008).

Another methodological consideration raised is that of insufficiently short follow-up periods in trials – typically at four- and/or twelve-month post-intervention. This makes it difficult to draw conclusions about the longer-term effects of self-management programmes (Rijken et al., 2008). However, Barlow et al.'s (2009) eight-year follow-up of ASMP participants, gives an early indication that some benefits of attending are maintained long-term.

Similarly, variations between reports on the effects of self-management education on healthcare usage need to be addressed. Some studies report reduced usage, others report no change: these largely overlook that patients

are given skills to improve communication with healthcare professionals, and encouraged to participate collaboratively in the care. Yet several studies did find improved communication was achieved (Lorig and Holman, 2003; Foster et al., 2007; Lorig et al., 1999). Thus, Bury et al.'s (2005) suggestion that this finding is disappointing rather misses the point that whilst the quantity of GP consultations remains unaltered, the quality may have improved. Few studies examined this; more attention appears warranted.

Likewise, few studies considered the cost-effectiveness of self-management interventions. Barlow et al. (2002) noted that individually-delivered courses were likely to be more expensive than group courses and that lay-led programmes would probably be less expensive than those provided by medical staff. Kennedy et al. (2007) found a reduction in healthcare costs, but longer-term analysis is needed. Furthermore, this addressed direct costs of delivering the programme, not the indirect costs to attendees (e.g. time off work, substitute care, travel expenses etc.) (Rijken et al., 2008).

### **Philosophical considerations**

A number of fundamental objections have been raised about self-management's underlying core values, which are again included in the interests of balance. For example, Fox, Ward, and O'Rourke (2005) pointed out that notion of the 'Expert Patient' ignores entrenched professional power which sees healthcare professionals *"cling to power in their engagements with patients, controlling information and dismissing efforts by patients to theorise or explain their condition"*. The national evaluation of the EPP's pilot phase found that professionals had not engaged in the process and few referred people to courses or knew about their content or rationale (Kennedy et al., 2004). Jones (2010) addressed the unpopular term 'Expert Patient' in his interview with Kate Lorig:



(Jones, 2010; pg.xiii)

Thus, the need to educate the professionals about EPP's collaborative approach and the tools and delivery systems to support self-management education (Battersby 2006) is confirmed. This supports Wilson (2001), who asserts that EPP's policy focus on empowerment of those with LTHCs, overlooks the fact that there is no corresponding strategy to challenge professionals' assumptions toward those with LTHCs. Similarly, Fox et al. (2005) found it paradoxical that Expert Patients must assume compliance and, simultaneously, a degree of taking control whilst Wilson et al. (2007) highlighted the same issue arises during the course. However, given that people with LTHCs need to manage their lives, including medical aspects of the condition, this suggests that EPP may accurately be reflecting and addressing the tensions that they experience.

However, some patients will not want responsibility (Fox et al., 2005), preferring to follow instructions. Barlow et al. (2002) suggest that this may mean that some groups who appear not to be served well by existing support programmes, are those who lack motivation and do not embrace the concept of self-management. These groups may require special attention (Barlow et al., 2002); however it is noteworthy that informed patients have the right to decline course attendance. I consider the issues around those non-attenders who are not well-informed now.

### **Pragmatic considerations**

Rijken et al. (2008) noted that an elementary level of self-management ability is a pre-requisite for successful self-management support programmes. For example, patients need to know about the existence of courses (knowledge); they need to speak the same language as the programme leader and other group members (oral communication, social support) they need to be

sufficiently literate to be able to read and understand the accompanying written materials (written communication); and they must be able to reach the location and to afford the costs of participation (manage resources). Inadequate access to such resources may represent a barrier to attend education programmes or to perform successful self-management for some people with LTHCs (Rijken et al., 2008). Reaching diverse and disadvantaged groups was recognised as a challenge for EPP (Kennedy et al., 2007). Older people, the less educated, those on low incomes or with cognitive or intellectual impairments, or people from ME backgrounds are considered the most disadvantaged (Kennedy et al., 2007). This is a rare acknowledgement of ME health inequalities, and the role that self-management interventions may play in this, amidst a paucity of evidence supporting their effectiveness amongst different groups.

Finally, tailoring self-management courses to the needs of individuals to overcome these barriers has been advocated and interventions need to be developed and evaluated with this in mind (Rijken et al., 2008). Yet such tailoring is in its infancy and there is no evidence to guide policy makers as to the best approach; Rijken et al. (2008) advocate that further research is needed to understand the barriers to self-management that different patients experience. This is central to the aims of the current thesis.

## **Summary**

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An international body of research has found ASMP and CDSMC/EPP to be an effective means of helping people with LTHCs to manage their daily lives. The UK national pilot of EPP was a success with suggestions made to overcome problems that were identified. British South Asians have benefited from the Programme and further research with these groups is needed to better understand cultural determinants of EPP's effectiveness. The current PhD will focus on exactly those issues.

## 2.4 Chapter Two Summary

The WHO and DoH advocate the use of self-management educational interventions to help reduce the burden of suffering caused by LTHCs. The need to actively involve members of ME communities and recognise their specific needs in order to improve their health self-management was identified in the policy literature. People from ME backgrounds in the UK experience substantial inequalities in their health, compared with other groups.

Community-based group interventions targeting specific South Asian communities are required, supported by culturally appropriate educational materials. Effectiveness data suggest that ASMP and CDSMC/EPP represent an effective approach to educate people with LTHCs how to improve their physical and psychological symptoms and learn new self-management skills. Yet a dearth of literature exists about the potential benefits of EPP amongst ME people, the potential barriers that they may face and what may be done to tailor courses to better meet their diverse needs.

# Chapter Three: **Method**

## Chapter Contents

### 3.1 Method

### 3.2 Research Rigour

### 3.3 Ethics

### 3.4 Chapter Three Summary

*Methodological evidence, collected during preliminary fieldwork and contributed to the design and methods adopted in this thesis, is presented in Appendix One. It comprises: EPP Leads' experiences, Translation of Course materials, South Asian health workers' guidance, and Local EPP position.*

## 3.1 Method

The previous Chapter outlined published literature that was considered in order to establish how best to design this research. This Chapter details the methodological factors that were necessary to formally operationalise this applied health psychology study. Starting with an epistemological overview of the different research paradigms, I then outline several analytical approaches and data-collection techniques that were considered. Next, I discuss concerns around validity of such data, before finally highlighting ethical considerations that were addressed.

### 3.1.1 Epistemological and philosophical underpinnings of research paradigms

This research aimed "to describe the experiences of living with a LTHC, identifying barriers to and facilitators of self-management practices, including

*attendance on a self-management programme, amongst people from South Asian backgrounds".* The first two objectives of this research, designed to achieve this aim, were to describe the experiences of delivering EPP to South Asian attendees, from the perspectives of EPP tutors from both White and South Asian backgrounds. The next objectives were to describe Punjabi Sikh people's experiences of living with arthritis, their perceived barriers and facilitators to self-management; and finally, their experiences of attending the EPP. The most appropriate methods of achieving these objectives are now considered. Willig (2003) argued that the research objectives determine the epistemological position that is necessary to meet a study's aim, this is considered now.

Traditionally, many scientific researchers adopted a positivist epistemological position that, in simplistic terms, assumes a straightforward relationship between objects, events, phenomena etc in the world, and our perception and understanding of it. Ashworth (2003) suggests that the positivist viewpoint characteristically accepts the existence of a 'real' world, of which individuals are part. He further argues that, in the positivist tradition, only observable events or testable propositions have a claim to truth e.g. psychological experiments in which psychological process are revealed, measured and modelled, in order to test hypotheses. Similarly, the empiricist epistemological position also assumes that the 'facts of experience' (Willig 2003, p.3) determine our knowledge of the world, through the systematic collection and classification of observational and experimental data. For example, traditionally, behaviourist 'objective' experiments manipulated variables and recorded the stimulus-response data. Both positivist and empiricist approaches typically collect nomothetic data, which, in health psychology research, are often obtained from written survey instruments.

However the subjective nature of human observation and perception is now more widely accepted. For example, the social constructionist approach acknowledges that historical, cultural and linguistic factors mediate our

experiences and perceptions (Willig, 2003). Unlike positivist and empiricist approaches, social constructionism does not assume a unified reality or knowledge, but understands that different perceptions and understandings of a phenomenon can co-exist.

Similarly, the phenomenological paradigm has an epistemological focus on experience, not a “real, knowable world” (Langdrige, 2007). Ashworth (in Smith 2003) cites Husserl's famous argument that phenomenologists should 'go back to the things themselves', as they appear to consciousness. Specifically, phenomenological research focuses on participants' perceptions of the world, and what it means to *them*:

*(Ashworth, 2003; p.13)*

Thus, phenomenological approaches avoid the determinism of positivist and empiricist approaches; rather they seek universals of human experience. Heidegger, who was one of Husserl's students and an early 'existential phenomenologist', went on to develop phenomenology in a way that emphasised the lifeworld Ashworth (2003). He argued that people's lived experiences may be specific in details, but share universal features including temporality, spatiality, subjective embodiment and selfhood. Heidegger argued that we are essentially perceptual in orientation, but alive to the constructed and social nature of experience (Ashworth, 2003).

Phenomenological studies use subjective and involved qualitative data-collection methods, which produce naturalistic, experiential accounts. These are analysed by the researcher, who acknowledges her personal influence on the research process. I return to the subject of data interpretation and hermeneutics in phenomenological research shortly. Further weight is given to

the strengths of a phenomenological approach, when considering its particular utility with South Asian participants in the current studies. As the previous Chapter demonstrated, cross-cultural research must engage with the population(s) under investigation, including those who may usually have little opportunity to contribute. Research with South Asian people living in the UK has consistently found that oral communication is preferred over the use of written materials (Hawthorne, 2001; Randhawa, 2005; Greenhalgh et al., 2005), even in literate patients (McAvoy and Raza, 1991). Similarly, when considering research methodology, Maly (2000) regarded qualitative techniques to be particularly appropriate for exploratory research that aims to identify what phenomena are taking place, such as in the present study. Furthermore, she suggested that qualitative research is pertinent with ME populations, about whom little is known and much is assumed from mainstream populations, to identify and overcome misperceptions about socio-cultural factors in health behaviours (Maly, 2000). Indeed, Berry et al. (1992) assert that qualitative approaches

(Berry et al., 1992; pg.315)

The aims and objectives of the current study require descriptions and interpretations of the meanings that phenomena have to those experiencing them. In summary, I decided that adopting a qualitative research paradigm was warranted in order to achieve the phenomenological research aims of the current study. The differing merits of several qualitative approaches are now considered.

### **3.1.2 Qualitative analytical approaches**

This section outlines the main considerations that determined the qualitative analytical approach best suited to answering the research question.

Qualitative psychological research explores and makes sense of subjective meanings of participants' experiences, from their personal perspective. It assumes that the way a participant talks about things in some way relates to their thoughts (Osborn, 2005), reflecting the way they "grasp reality" (Pinker, 2007). The qualitative paradigm uses an inductive approach that makes data-driven inferences from participants' examples; this is particularly important in the current area of exploratory, descriptive research, with participants about whom little is known.

Several qualitative approaches examine features of human verbal interactions, in order to better understand the social context in which the phenomenon being investigated occurs. For instance, Conversation Analysis (CA) considers how participants understand and respond to each other in terms of, for example, turn-taking, topic initiation and closure, agreement and disagreement etc. (Murray, 2003). Similarly, Discourse Analysis (DA) (Willig, 2003) considers language to be a "social performance" (p.159), and focuses on how people linguistically manage accountability and stake in everyday life.

However, neither technique is primarily concerned with *understanding* participants' experiences, which is the focus of the current research. Furthermore, both CA and DA study naturalistic data in the form of extant audio/video recordings of the topic under examination, which were highly unlikely to exist in this under-researched area of investigation. CA does not usually consider interview data to be naturalistic, nor does it permit simulations of naturally occurring conversations, so the creation of such data was methodologically (and ethically) implausible. Both CA and DA were rejected.

The next qualitative approach to be considered was Grounded Theory (GT). This starts with a general research question, before building abstract theoretical categories from the analysis and data synthesis. However, interpretation of



data relating to participants' personal understandings is not permitted in GT (Charmaz, 1995). This would preclude the level of psychological insight that the research aims demanded. Furthermore, data-collection and analysis occur simultaneously in GT research, with 'theoretical sampling' of participants to check and refine emergent categories. As the time constraints of this study (for example, the likely need for an interpreter's involvement in Study Three) meant that data-collection was likely to occur over a relatively short time period, the opportunity to analyse each data-set before deciding on the next participant was not considered feasible. Of most significance to this study, theoretical sampling intends to confirm the categories that have already been identified with GT analysis, and not to represent a particular population. As participants' tutor status, or ME and LTHC status were pre-requisites of the study's aims, it was apparent that GT would not be an appropriate data-collection and analysis method, and was therefore excluded.

The final qualitative approach to be considered was Interpretative Phenomenological Analysis (IPA). IPA is considered particularly useful in novel, under-researched, complex or ambiguous areas (Osborn, 2005). As there is no published research specifically examining either White, or ME EPP tutors' experiences of delivering EPP to ME attendees, Studies I and II are considered novel. Furthermore, tutors' delivery experiences with attendees from different ethnicities, on both English and South Asian language courses, may reveal socio-cultural issues that could be considered complex. Similarly, Studies IIIa and IIIb are novel as they ask Punjabi Sikh women about living with arthritis and their EPP experiences, in what are believed to be the first interview studies of these subjects. Interpretative and descriptive methods of research are specifically recommended by cross-cultural psychologists (Berry et al., 1992).

The aim of IPA is the detailed exploration of individuals' psychological perspectives of a topic (Smith et al., 1999; Reid et al., 2005). Likewise, in his influential position paper, Jonathan Smith suggests:

(Smith, 2004, pg. 48)

No single formula exists as to how to perform IPA, although good psychological work encompasses different levels of analysis (Osborn, 2005), starting with descriptive analysis, with open codes identified from the text. Next, during interpretative analysis, connections are sought between themes to identify clusters of themes, which are interpretations of the participant's experiences (Smith et al., 1999). This is known as a double hermeneutic approach, as it represents the researcher's interpretation of the participant's interpretation of the phenomenon. As mentioned in section 3.1.1, the issue of hermeneutics – derived from Ricoeur's theory of interpretation – is important in such work. IPA uses the hermeneutics of meaning-recollection ('empathic hermeneutics' - Smith and Osborn in Smith, 2003) and aims at faithful disclosure of the phenomenon under investigation e.g. of living with a LTC, to inform others about the nature of that experience. Heidegger argued that, like constructionists, we live in a world that we constantly interpret: we are hermeneutic (interpreters)(Ashworth, 2009).

Finally when undertaking IPA, phenomenological analysis is undertaken, where the participants' data and the interpretations so far found, are questioned critically for alternative meanings or understandings, and deeper structures (e.g. time, paradoxes etc.) are identified. These hermeneutics of suspicion ('questioning hermeneutics'; Smith and Osborn in Smith 2003) can be employed in IPA research to discover what is behind the phenomenon being analysed. This allows a much deeper interpretation to take place, which can challenge the surface account provided by the participant. This analytical depth would clearly permit the detailed explanatory insight that the study's aims demanded, into participants' personal understandings of their experiences.

Another deciding factor in considering the most suitable approach for the present study, is IPA's ability to allow deep issues to surface and make unheard voices understood (Larkin et al., 2006). Thus, IPA may be particularly appropriate for understanding previously unheard tutors' experiences of delivering EPP to South Asian people, and Punjabi Sikh people's experiences of living with arthritis, and for allowing their potentially deep-rooted cultural barriers (and facilitators) to self-management participation to appear, and to understand their experiences of attending the EPP.

This section has examined the different qualitative analytical approaches that I considered, before deciding upon IPA as the most appropriate for this study. A detailed account of how this analysis was undertaken in each study, is presented in Chapter 4. The following section outlines the justification that informed the best data-collection technique.

### **3.1.3 Qualitative data-collection techniques**

IPA can be undertaken on a variety of media, for example, diary data, focus groups, or interviews (Langdridge, 2007); these will each be considered now, starting with diary data.

Autobiographical life-story data around a particular experience can be collected from diaries for IPA research, providing rich narratives of life events that participants deem important (Langdridge, 2007). However, the research Centre's previous experience of studying EPP tutors, suggested that these unpaid volunteers may be reticent to commit to this time-consuming exercise. This may deter tutors from the already small research population from participating in the first two studies. As discussed in the preceding Chapter, South Asian participants in previous research have shown preferences for

verbal over written materials, and literacy cannot be assumed. Crosby et al. (2009) argued that amongst populations with low literacy, the use of face-to-face interviews or audio-assisted data-collection methods were necessitated. Obtaining data derived from participants' diary entries was therefore dismissed as an IPA data-collection option.

The potential utility of focus groups (FGs) to gather data for IPA will now be considered. Sometimes known as focus group interviews (Wilkinson, 2003), FGs engage a small number of people (4-8, Wilkinson, 2003) in a group discussion around a particular topic, and are typically facilitated by the researcher. Group members are encouraged to interact with each other, responding to and commenting on others' contributions, thus generating rich data for analysis (Willig, 2003). Transcripts are used to generate themes that are present amongst the FG's members (Smith 2004). However, Smith (2004) expresses ambivalence regarding their use in IPA research, which, as in the current study, aims to obtain detailed descriptions of participants' individual lived experiences (Langdridge, 2007). Thus, the focus group format might create group dynamics that subverted this aim. For instance, if a participant was influenced by a more forceful personality within the group, or by someone perceived to be of higher status, s/he may become reticent at sharing a personal aspect of the health experience. Any agreement expressed by the FG, may reflect the dominant view ('assumed consensus' Smith 2004, p.50), so losing the important idiographic accounts that the current research question requires. Wilkinson (2003) further highlights that confidentiality is a particular issue with FG research, even if agreements are reached within the group at the outset. This may have had the potential to deter potential participants from an already small potential research population, from participating in the present study. FGs were therefore discounted as a data-collection technique.

Finally, interviews will be discussed as a source of IPA data-generation. Interviews are the chosen method for most IPA researchers, as they enable the participant to articulate many details about their experience (Langdridge,

2007), and permit a deep level of understanding about participants' subjective meanings and experiences (Wilkinson, Joffe and Yardley, 2004). Interviews allow participants to give an insider's view of their worlds, by giving meaning to the cultural and social contexts of their experiences (Ong and Richardson, 2006), which may be of particular import in the present study. Participants are unlimited in their range of spontaneous responses, which provides the potential for eliciting unexpected insights into the phenomenon under investigation, which may again be relevant to this under-researched and little understood area. Interviewees can be asked to reflect on past and present experiences (Sim and Wright, 2000), which may identify aspects of psychological change, which could prove particularly helpful in Study IIIb, after participants have attended EPP.

This section identified IPA as the most appropriate analytical approach, and interviews as a suitable data-collection technique to address the research question. I will now highlight the potential drawbacks of IPA interview studies, and the steps that were taken to overcome them to operationalise this study.

### **3.2 Trustworthiness/Quality**

The applicability of the quantitative concepts of 'reliability' (the likelihood of repeating the research and obtaining the same outcome) and 'validity' (establishing that the research examined what it set out to) (Sim and Wright, 2000) have been critically examined by qualitative researchers. This section starts by considering some of the ways that have been proposed to enhance the 'reliability and validity' of qualitative research, before I present now more widely accepted criteria for establishing the trustworthiness and quality of qualitative data.

## **'Reliability'**

'Reliability' of qualitative data-analysis can be improved through inter- and intra-coder checks (Smith et al., 2009). Two researchers recode the qualitative data some time after the initial coding has taken place, to ensure that the same categories are identified. Similarly, reliability of qualitative data-analysis can be checked through member validation (Sim and Wright, 2000). This ensures that participants consider the themes arising from analysis to be accurate. Issues with these methods of establishing reliability in phenomenological research will now be addressed.

Much qualitative research, including this study, does not intend to be repeatable, and differing interpretations of the same data may be evidence that alternative realities exist (Marks and Yardley, 2004). Reliability checks are not routinely considered appropriate for IPA studies (Willig, 2001), and were not undertaken in the present study. The iterative nature of IPA analysis means that themes develop throughout the ongoing analytic process, and are expected to change from those initially identified. Instead, the reliability of the analysis is established by returning to the transcript, to ensure that identified themes are indeed present in the participant's account; this is how the reliability of the present study was confirmed. This is considered to be a strength of the approach, which seeks to identify deep issues that may not be immediately apparent to a researcher unfamiliar with the data. Furthermore, IPA analysis represents the researcher's interpretations of participants' understandings, experiences etc; the approach explicitly acknowledges that other multiple explanations may exist.

For the same reasons, member checks by research participants are not necessarily recommended in IPA research (Smith, 2007). Power dynamics may prevent participants from questioning the analysis, yet it is unlikely that any participant would be able to entirely endorse another's interpretation of his/her experience. Member checks were not, therefore, performed in the current

research. Furthermore, literacy (in any language) could not be assumed for Punjabi Sikh participants in Study III, and the English-language research report may have represented a barrier to some participants. Issues of confidentiality arise when discussing findings with small groups of participants, such as those in the present study. Participants, who knew each other, were assured that nothing they said would be discussed with other members of the group and their real name would never be used in reports and publications. However, they may have found it possible to identify each others' accounts given the small numbers involved in this research.

### **'Validity'**

'Validity' of interview research can be enhanced through audit (Sim and Wright, 2000), whereby a paper-trail (Osborn, 2005) of evidence for the researcher's interpretations of experiential evidence that are generated, can be examined and critiqued. This forms the basis of a convincing argument supporting the findings. Whilst not appropriate to append my extensive analytical notes in this thesis, my Findings in Chapters 4-7 are supported by quotations, and Appendix Two contains a worked example of a small section of my analysis. However, Sim and Wright (2000) assert that the concept of validity may not apply directly to qualitative data, as it assumes one single formula accounts for phenomena investigated. These views fit the epistemological position of the current study, as previously discussed. Similarly, the transient nature of the phenomena often investigated qualitatively may not lend themselves to validation (Chamberlain, Camic and Yardley, 2004) – *"people do not repeat themselves verbatim in different interviews about the same subject!"* (Sim and Wright, 2000). Furthermore, the adoption of a pragmatic approach to applied research, such as in the current study, is supported by Porter (2007):

(pg.79)

## Trustworthiness

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The process of establishing the quality of qualitative research by using reliability and validity criteria that were developed for use in the quantitative paradigm, is now widely rejected by qualitative researchers (e.g. Smith et al., 2009). Instead, quality is better assessed by consideration of its trustworthiness, upon criteria developed amongst qualitative researchers. Given the vast scope of the qualitative paradigm's range of potential research questions and associated methodologies, it is unsurprising that no single set of criteria has emerged as a gold standard for qualitative excellence. However, two such approaches that offer appropriately wide-ranging quality guidelines (Smith et al., 2009), have found credibility amongst their peers. In their influential work on this subject, Lincoln and Guba (1985) proposed four ways to establish the trustworthiness of a study: by considering its credibility, transferability, dependability and confirmability. Favoured more recently by Smith (2003) for use in qualitative psychology and specifically with IPA studies, are Yardley's (2000) four principles for assessing quality: sensitivity to context, commitment and rigour, transparency and coherence and impact and importance. These criteria are outlined in Box 3.1, on the next page.

It is apparent that some overlap exists between areas of these criteria, which I have highlighted in similar colours in the box above; detailed discussion is beyond the scope of this work. However, this is not intended to give the impression that these criteria are the same, or the terms interchangeable; I have merely used these similarities to structure the remainder of this section.



<b>Lincoln and Guba (1985) (Trustworthiness)</b>	<b>Yardley (2000): (quality)</b>
Numbers in brackets refer to the subsection of this chapter in which the issue is addressed	
<b>Credibility</b> (3.2.2)  The plausibility and integrity of the study	<b>Sensitivity to context</b> (3.2.1)  Consideration of the socio-cultural situation of the study, reference to existing literature, material obtained from participants
<b>Transferability</b> (3.2.4)  Whether results might be applied to contexts other than the research setting	<b>Commitment and rigour</b> (3.2.2)  The appropriateness of sample for the research question, attentiveness to participant during data-collection and thoroughness of analysis
<b>Dependability</b> (3.2.3)  The clearly defined research processes that are open to scrutiny	<b>Transparency and coherence</b> (3.2.3)  The clarity with which each stage of the research is presented  Complete and logical write-up
<b>Confirmability</b> (3.2.3)  Where study outcomes are demonstrably drawn from the data	<b>Impact and importance</b> (3.2.4)  The extent to which the work tells the reader something of interest, usefulness, or importance

### Box 3.1 Suggested criteria for evaluating qualitative research quality

#### 3.2.1 Sensitivity to context

Yardley (2000) argued that sensitivity to the context in which a study is undertaken can be established by considering features of the research including attention to the socio-cultural situation of the study, references to existing literature on the topic under investigation, and awareness of interactional difficulties of obtaining material from participants.

Evidence of the high level of attention that I paid to the overall socio-cultural context of the present research, which is pivotal to the current study, is evidenced by the fieldwork that I undertook during the design phase, and can be found in Appendix One. Chapter Two described relevant literature that has been published across the interdisciplinary topic areas considered in this thesis. The following considers the steps that I took to minimise interactional difficulties during data-collection.

Helman (2007) noted that attributes of the researcher, including age, gender, ethnicity, dress, body language, tone of voice and religious or political background, may influence the data collected; the most pertinent of these are addressed here. Much of the literature around gender biases in interviews assumes that most problems arise when a female interviewee is being interviewed by a male interviewer, particularly if the topics of discussion are of a sexual or gynaecological nature. As we were not discussing such sensitive issues, and only two Study I participants were male, my female gender is unlikely to have unduly biased the responses from participants.

Whilst the last of these potential biases to be discussed here, ethnicity, is less likely to be an issue with the White participants in Study I, as my own ethnicity is the same as theirs, this could be a factor in the studies with South Asian participants. I address ethical issues around cultural sensitivity in section 3.3 of this Chapter, and my reflexive account deals with this in more detail in Chapter Eight. Where these issues are believed to have been a factor in the present research, they are highlighted in the relevant Chapter. Fontes (2008) urges caution in the reductionist assumption that ethnic matching automatically relieves cultural dilemmas from any interview. Indeed, the other potential biases (described above) are likely to be more obvious to someone from the same ethnic group.

A motivational bias may occur when the interviewer or interviewee tries to provide a particular outcome, for example, the 'best answer' to an interview

question (Fontes, 2008; p.40). My perceived professional status for example, as 'academic' or 'researcher' could lead participants to make certain assumptions about what they believe I require of them, thus biasing their responses. Similarly, a participant who perceives her/himself to be of lower educational or socio-economic status may potentially feel intimidated, and less likely to speak to me openly, for fear of negative social value judgment. Equally, I might unwittingly assume inappropriate authority, and so alienate my participants. Conversely, the likely demographic of EPP tutors and arthritis patients as older than me, could lead them to assume authority over me during the interview, or to doubt the importance of the interview (Fontes, 2008). Similarly, my dependence on participants for their co-operation and access to their thoughts and experiences gave them some power over the direction of interviews. I hope that by speaking with interviewees and interpreters prior to commencing the interviews may have reduced mutual misperceptions. I made every effort to put participants at their ease prior to and during interviews, in a deliberate attempt to address this issue. However, I acknowledge the inevitable influence of these factors.

This section has highlighted my understanding of the importance of the first of Yardley's (2000) criteria for assessing the quality of qualitative research: the sensitivity to the context of the study.

### **3.2.2 Commitment and rigour/credibility**

The rigour of a study can be assessed by considering the thoroughness of a study, for example by examining whether the sample selected is appropriate to answer the research question, and the completeness of the analysis (Smith, 2003). Similarly, Lincoln and Guba's (1985) credibility criterion examines the plausibility and integrity of the study. These application of these concepts in the current work, are considered now.

Chapters One and Two of this thesis provided a summary of the context and rationale for the whole work, grounded in the extant literature across the relevant interdisciplinary areas. Similarly, Appendix One provides detailed description of the Fieldwork that guided the formative stages of this work. This establishes the thoroughness with which I approached the present work, from designing the research question, establishing the most appropriate methods to answer this, and the academic justification for these decisions.

This Chapter outlines the general approaches adopted in the present work, whilst detailed explanation the research processes of each Study is provided in the relevant Chapter. Many specific issues can potentially compromise the quality of qualitative research, which essentially has a subjective nature and local focus (Stringer and Genat, 2004), such as the current study, including the interview process and, consequently, the data collected and its subsequent analysis. The appropriateness of each sample can be established with reference to the 'Participants' section in each Study's Chapter, whilst the thoroughness of analysis is determinable by considering my multi-layered approach to this, again detailed in each Study's Chapter, and demonstrated in my presentation of each Study's Findings. Additionally, a worked example is provided for reference, in Appendix Two. However, the issue of sample size warrants specific attention in the present work, and is discussed below.

Addressing misunderstandings around perceptions of small sample sizes, Reitmanova (2008) asserted that that the socio-cultural meaning of health and illness experiences are immensely important in social science research, not simply the frequency with which experiences occur. Conrad (1990) argued that no definitive formula exists to determine an appropriate number of study participants, and sometimes  $N=1$  may suffice. Importantly, Smith (2004), and Smith and Eatough (2007) specifically advocate the use of small samples ( $<10$ ). This allows for detailed idiographic analysis of participants' richly nuanced

accounts of a particular experience, without losing the texture of individuals' experiences.

**Table 3.1** shows the total number of participants who were recruited into each study of the present research. The total number of participants across the three studies was 18, and the total number of interviews conducted was 22. As the following shows, this small number of participants fits with recommendations using the IPA approach.

**Table 3.1: Numbers of participants and interviews by Study**

Study no.	Study description	No. of Participants	No. of interviews
Study I	White tutor interviews	5	5
Study II	South Asian tutor interviews	3	3
Study IIIa	Punjabi Sikh community interviews, pre-EPP	10	10
Study IIIb	Punjabi Sikh community interviews, post-EPP	*	4
<b>Total number of Participants</b>		<b>18</b>	
<b>Total number of interviews conducted</b>			<b>22</b>

*\* Follow-up interviews with sub-sample of Study IIIa Ps*

Flowers' IPA review (2005) contained sample sizes ranging from 1-40, with a mean sample size of 14 participants. Furthermore, the nature of the study's aim ultimately determines the most appropriate sample size. Large sample sizes would compromise the idiographic emphasis of the approach, which demands detailed phenomenology, insightful hermeneutics, and nuanced analysis (Smith, 2008). Hence, in the present research, each Study's aim determined the

most appropriate sample size. In addition to the five participants recruited for Study I and three participants for Study II, 10 participants were recruited for Study IIIa. It was correctly anticipated that this would allow for attrition during Study IIIb, which involved four follow-up interviews, giving an appropriate sample size across the whole study. Studies I and II can be considered 'multi-perspectival' (Clare, 2002 in Smith, Flowers and Larkin, 2009) as they explore the phenomenon of delivering EPP to South Asian attendees, from the perspectives of both White and South Asian tutors. Study III is longitudinal in design, involving interviewing some participants both before, and then again after they had attended EPP; I return to this in Chapter Seven. Both are considered 'bolder designs' by Smith (pg.52, 2009).

In this section I have shown the steps that I undertook in order to establish this work's commitment and rigour (Yardley, 2000). Specifically, I have demonstrated that small but relevant samples sizes are the norm in phenomenological research, with 22 interviews conducted with 18 participants considered appropriate to meet the current research's aims.

### **3.2.3 Transparency and coherence**

Yardley (2000) considers that the next two quality criteria, the transparency and coherence of qualitative research, can be established by considering the clarity with which each stage of the research is presented and the completeness and logic of the write-up. Similarly, Lincoln and Guba (1985) assert that the dependability of a study, relates to having clearly defined research processes that are open to scrutiny and that its confirmability is established by having outcomes that are demonstrably drawn from the data. These issues are considered now.

The present Chapter represents my understanding of the importance of the need for transparency and coherence of research processes, by detailing my

Methods and discussing their potential shortcomings. Additionally, I include Ethical considerations both later in this Chapter and in Appendix Three.

Furthermore, the present work meets both Yardley's (2000) transparency and coherence criteria, and also Lincoln and Guba's (1985) notion of dependability by my detailed presentation of every Study's:

- objective(s)
- participants' demographic data and recruitment processes
- data-collection
- translation and interpretation processes, where appropriate, which acknowledge the central importance of the translators and interpreters in this work
- analytic processes
- findings, supported by quotes

discussion of findings, related to literature and my previous findings (where appropriate). The latter two of these are particularly pertinent to establish the present study's confirmability (Lincoln and Guba, 1985). I again demonstrate my fulfilment of these criteria in Chapter Eight, where I present my thesis implications and conclusions, only after discussing the Methodological considerations that may have influenced the overall work.

### **3.2.4 Trustworthiness: Transferability/Impact and importance**

Factors that could potentially affect the trustworthiness of my data-collection and findings are addressed here.

Guba and Lincoln (1985) used the term 'transferability' as a criterion for qualitative research quality, which considers whether the results of a study might be applied to contexts other than the research setting. Known as 'generalisability' in the field of quantitative research, this quality criterion differs

greatly between the qualitative and quantitative paradigms and has generated considerable debate (Chamberlain, Camic and Yardley, 2004). The latter uses large-scale representative samples of the study population, to generalise findings to the wider population. However, as Matelrud (2001) highlighted succinctly:

(Matelrud, 2001; p. 485).

Qualitative studies, including the present one, may, however, examine a specific phenomenon in a particular individual or group, to understand the internal dynamics of that phenomenon. As generalisability beyond the individual or group is not an aim of the research, it is, Willig (2001) argues, not an issue. Yet if, as in this study, the findings are likely to have implications beyond the participants, the research may identify explanations that potentially apply to similar others (Willig, 2001). Although sweeping generalisations may not be appropriate, comparisons with other cases within the study and reference to other similar studies, may serve to start theory-building and represent transferability.

Purposive sampling of homogenous participants are necessarily used in IPA studies, with no pretence of randomization (Smith and Osborn, 2003; Smith, 2009) in order to achieve generalisable results, as routinely undertaken in much quantitative work. The authors suggest that such research should say a lot about study participants, something about their broader peer-group, and little about people beyond that group. In time, however, IPA studies may start to become more transferable, as a body of evidence is built – although the pace of the generalisation will, necessarily, be much slower (Smith and Osborn, 2003).

These 'working hypotheses' (Guba and Lincoln, 1985; p. 297) may be transferable to other contexts – although, importantly, this will depend on the extent of similarity between those precise contexts. The transferability of findings between, for example, two comparable populations living in different



parts of the same country, could not be *established* by studying only one of those populations (Guba and Lincoln, 1985), but *theorised*. With IPA studies, Smith (2009) suggests that the reader should evaluate the theoretical transferability of findings by considering their personal and professional experiences, the extant literature, and the likely similarity between people and contexts of interest.

Finally, Yardley (2000, in Langdridge) argues, somewhat contentiously, that the impact and importance that a study's findings have on the wider world contribute to its validity. Less applied studies that advance methodological or theoretical boundaries are also of intellectual value. Whilst a contribution to thinking appears to be a more widely-held view (Langdridge, 2007), the applied nature of this thesis appears to fulfil this criterion. The impact and importance of the present work has been strengthened by the dissemination outputs, which are listed in Appendix Five. Smith (1999) argued that qualitative research should be judged primarily on how illuminating it is of the particular cases studied and that the 'micro-level theorising' should be richly informative of those particular individuals.

This subsection has shown that whilst the current IPA study does not intend to have widely transferable results, some theoretical transferability may be appropriate.

### **Summary**

In this section, I have addressed some of the complexities around establishing the trustworthiness of qualitative research, highlighting my necessary blend of both evidence-based and pragmatic approaches to addressing the research aims.

#### **3.2.5 Interpreters and translators**

When considering the rigour of the present study, the influence of interpreters and translators must be examined. As the South Asian participants in Study III could not be assumed to be English-speakers, it was anticipated at the outset of the current work that it might be necessary to employ interpreters and translators to gather interview data for translation and transcription. Efforts to locate previous studies or guidelines for conducting psychological research with interpreters and translators in IPA studies were made; no published paper was located. However, national guidelines and cross-cultural research in related disciplines were identified, and the following discusses how these were synthesised into the present, methodologically novel, study, to maximise rigour.

Cross-cultural research is recognized as an illuminating component of public health research, although it raises complex issues around cross-language data-collection, which should be regarded as challenges rather than obstacles (Pitchforth and van Teijlingen, 2005). I have attempted to adopt this approach here. Yet Larkin and colleagues (2007) note that cross-cultural research has focused on translating and validating quantitative measurement instruments, largely overlooking discussions about how best to construct multilingual qualitative tools, such as interviews. However, the increasing trend toward research being undertaken in English-speaking cultures with people who speak little or no English (Pitchforth and van Teijlingen, 2005) has encouraged the challenges of interpretation and translation on study findings to be addressed (Larkin et al., 2007). The challenges considered most pertinent to the current study are discussed now.

### **Interpreters**

The Scottish Executive (2004) defines public service 'Interpretation', including in Health, as "The conversion of speech from one language... to another", whilst the role of the Interpreter "is to facilitate communication between two individuals...". They suggest that interpreters should possess a good command of both English and the target language, and familiarity with and objective understanding of both cultures. They should be professionally competent in the

relevant interpreting techniques, including a sound knowledge of the terminology in the area of work (Scottish Executive, 2004).

Wallin and Ahlström (2002) agree that the interpreter's cultural and linguistic competences are important factors that impact on research findings. For example, Kapborg and Berterö (2002) identified potential threats to validity at different points in the interview process. A threat arises when the researcher, whose first language is English, addresses a question in English to the interpreter, whose first language is *not* English; another during the interpretation by the interpreter from English into the target language, and again when the interpreter interprets the interviewee's responses into English. In the last situation, the researcher may be unaware if responses have been summarised and/or modified by the interpreter (Kapborg and Berterö, 2002), albeit, as the following shows, unintentionally or unavoidably.

Temple and Edwards (2002) highlight the 'dazzling array' (p.3) of possible word combinations that could be available for interpreters to convey meaning, rather than there being an identical word match in different languages. Furthermore, methodological issues arise around the meanings of concepts and how to convey difference, when conducting research with interpreters (Temple, 2002). Thus, linguistic equivalence between languages cannot be assumed, with the British Psychological Society warning "*that a sentence with 4 English words takes 20 words to interpret*" (pg3.).

Birbili (2000) and Tribe (2007) both support the widely accepted view that in order to help overcome these unavoidable issues, the conceptual equivalence of cultural meanings should be the primary aim of interpreting. Employing interpreters who are research trained may help further mitigate some of these factors (Kapborg and Berterö, 2002), although the realistic availability of such multiply qualified professionals is not considered!

Other influential factors requiring consideration in the present study include deciding upon an interpreting style e.g. simultaneous vs. consecutive, active vs. passive (Wallin and Ahlström, 2002, Fontes, 2008). Both interpreters in the present study preferred an active, simultaneous style, which Pitchforth and van Teijlingen identified as advantageous as this increases rapport and "flow" in interviews. This is discussed further in individual Chapters. The British Psychological Society produced guidelines for Clinical Psychologists working with interpreters in therapeutic settings, which I adapted for use in this study (BPS, 2006). They highlight the need to pre-determine with the interpreter whether the gist of the conversation is sufficient, or if verbatim interpretation is required. Verbatim interpretation that conveyed the conceptual equivalence was a pre-requisite for the present study. The BPS guidelines also advise consideration of the best seating arrangement. My interpreter(s) agreed that an equilateral triangular arrangement is usual, so that two people are not sitting together opposite the third person; this was adopted in all the Study IIIa and IIIb interviews. Both Fontes (2008) and the BPS recommended identifying the dialect of the language spoken by the service user, which allowed me to identify Punjabi as the dialect my participants spoke. This was invaluable because, as a novice researcher, I had not previously been aware of different Punjabi dialects; had participants spoken, for example, Mirpuri Punjabi, and I not checked this, the back-translator in Study IIIb would have been unable to help.

Pitchforth and van Teijlingen recommend that researchers working with interpreters develop an effective relationship with the interpreter to help identify and overcome the issues discussed here (Pitchforth and van Tiejling, 2005). Similarly, both the BPS (2006) and Fontes (2008) also advocate a pre-appointment meeting with the interpreter, to familiarise each other with mutual needs that will be required to achieve the appointment's objectives (e.g. key terms and meanings, interpreting style preferences), suggesting that this will engender a comfortable atmosphere for the interview. They further advise that the interpreter is asked to afford an appraisal of cultural, religious and behavioural matters of relevance to the service-user (BPS, 2006). This

(somewhat paternalistic) advice does not consider that the interpreter may not know the interviewee, and hence what socio-cultural factors are influential, raising serious concerns about stereotyping, which may actually be counter-productive. Rather, Temple (2002) argues, the interpreter will bring her/his own perspectives, "which are woven into their social interactions" p.853), including research interviews. Acknowledging this, I held constructive pre-interview meetings with the interpreters in this study, without asking for a cultural update. Booking at least double the normal time for the interview, to allow adequate time for the interpreting process, was, however, a BPS suggestion that I adopted.

The BPS (2006) proposes matching the service user and interpreter's nationality, religion, age and gender, to minimise these dynamics. I believe I achieved these with the exception of age; the two interpreters were younger than interviewees.

In their systematic review of cross-cultural interviews with interpreters in nursing research, Wallin and Ahlström (2002) were generally critical of the lack of attention that studies paid to the interpreter's pivotal role in the research process. Similarly, Pitchforth and van Teijlingen (2005) argue that the interpreter's influence should be acknowledged, whilst Fontes (2008) asserts that the interpreter's power cannot be underestimated. Indeed, Wallin and Ahlström (2002) suggest that how explicitly this factor is addressed, is an essential determinant a study's trustworthiness. This thesis therefore unequivocally addresses the interpreters' / translators' roles in the present study, in each relevant Chapter.

### **Translation and back-translation**

Having conducted interviews with an interpreter, I would then need to have the Punjabi sections of the audiofiles translated into English, prior to transcription. The Scottish Executive (2004) define translation as "the conversion of written text from one language to another". The role of the translator is to work "... with the

written word, meaning-fully re-assembling the fragments of communication from the source language to the target language. The translator provides his/her own view of the meaning of the original text" (Section 5. Scottish Executive, 2004). It is apparent from this that similar complexities to those around interpreting arise in the translation of research data, such as retaining conceptual equivalence, and the influence of the translator. Larkin et al. (2007) are particularly critical of research that fails to recognize the role of translation on data and its subsequent analysis, which ultimately influences the study's final outcomes. In recognition of the importance of these challenges, the following outlines translation guidelines and relevant research that shaped how translation was undertaken in this study.

The International Medical Interpreters Society have produced national guidelines for medical translations in the US (IMIA, 2009), suggesting that without such guidelines translation management may be subject to 'constant improvisation' (p.2). Whilst the translated interview transcripts in the present study will never be published in their entirety, and my study does not attract the same potential legal implications as a poorly-translated medical document, many of the basic issues are relevant. For example, IMIA highlight a simple mistake of translation where "disorder" in the medical context source language was mis-translated to mean a sense of confusion or mess, in the target language. Clearly such subtle shifts in meaning have implications for interview data that requires close analysis, and wide dissemination. To overcome such pitfalls, IMIA describe a competent translator as having "native, or near-native" (p.3) formal language proficiency, analytical abilities, and deep cultural knowledge in both the source and target languages. Whilst neither translator involved in the present study is formally qualified as such, one person who undertook translation is a multi-lingual qualified professional NHS interpreter, whilst the other is a professional researcher with experience in conducting qualitative health psychology interviews in Punjabi, and translating them. Thus, both translators are considered sufficiently proficient to undertake this work.

Temple and Young (2004) suggest the choice of when in the research process (e.g. as early as possible vs. as late as possible) and how to translate (e.g. with the interviewing interpreter vs. an unconnected translator) are often determined by the time and financial resources available to the researcher, as 'Translating into English is expensive' (pp.174)! The time constraints of the present study required that interview data were translated as soon as possible after the interviews, in order that I may commence the lengthy process of analysis. It was felt that the interpreters were competent, aware of the context of the research, and the translation process would be facilitated by their recollection of the interviews, reducing the time taken to produce transcripts. Budgetary availability allowed me to pay them for translation and transcription of Punjabi interviews. Issues around this are discussed later in the Thesis.

In an early phenomenological cross-cultural nursing study, Twinn (1997) explored the influence of translation in qualitative research. Despite no significant differences being found in the major categories generated from Chinese and English data when two translators were involved, some minor differences were identified. The importance of using only one translator to maximize the reliability of the study was also demonstrated. However, if more than one translator is used, the reasons for this should be clearly discussed (Wallin and Ahlström, 2006). As different translators were necessarily used for Studies IIIa and IIIb, I address this in more detail later in this thesis.

Twinn (1997) also suggested that her findings demonstrate particular problems in using translation in phenomenological research designs, especially where the grammatical structure of the two languages is dissimilar (for example different use of tenses and personal pronouns). This challenge is now refuted. As previously detailed at length, current leaders in qualitative research advocate that a pragmatic approach to methodology is adopted to suit individual study's aims. Indeed, in his reflection on the development of IPA and its contribution to qualitative research in psychology, Smith (2004) identified that the horizon is expanding in terms of both potential participants and data-collection. He argued that the increasing interest in conducting IPA research

with people for whom English is not their first language will necessitate that guidelines for conducting IPA studies are adapted when researching other groups. The present study represents one such adaptation. Explicitly addressing IPA studies involving interpreters and translators, Smith further suggests that consideration is given to whether the gains from speaking to a particular group sufficiently outweigh the costs from not speaking the same language:

(Smith, 2004, p.50)

I believe that the need to understand the factors influencing ME people's experiences of living with a LTHC and their self-management choices has been clearly identified, and entirely warrants this methodologically challenging approach. By overtly addressing the influences of interpreters and translators on this study, I hope to address Twinn's concerns about reliability and validity when using interpreters.

When considering methodological rigour in research involving translations, Pitchforth and van Teijlingen (2005) advocate that the accuracy of the translation should be confirmed. Yet the IMIA do not recommend the back-translation of a professionally translated text, stating it may fail to identify contextual and usage nuances in the target language. Indeed, meaning conveyed in the original may be lost, rendering the back-translation inaccurate (IMIA, 2009). As neither of the translators were professionally qualified, a decision was made to verify the transcripts, without performing a full back-translation. This is discussed in the relevant study Chapters.

This section has highlighted the many challenges – pragmatic and methodological - of conducting qualitative IPA research with interpreters and



translators, which have been considered in the present study. Attempts to minimise risks to reliability and validity have been discussed, whilst acknowledging the interpreters' and translators' critical influence in this study.

This section has shown that I will explicitly acknowledge my own influence on the research process, in this thesis.

### **3.3 Ethical considerations**

Coventry University Research Ethics Committee approval was obtained prior to the commencement of the research interviews (please see Appendix Three). As participants were being recruited through community sources and interviewed in non-NHS establishments, NHS Ethics approval was not required. The following details some of the principal ethical issues that were considered during the course of this study.

#### **3.3.1: Cultural sensitivity**

Fontes (2008) considers cultural competence to be an ethical issue. I attended Coventry University's cultural competence training course. The course highlighted the ways in which human existence is culturally-situated in ways that may not often be overtly examined, giving general examples of different cultural understandings of e.g. time-keeping, appropriate manners, eye contact etc. Of relevance in the present study, cultural differences around religious and spiritual beliefs and practices, and health beliefs including healing and medical practices were also mentioned. Guidance around culturally inclusive communication and interviewing skills was particularly pertinent for me: for example, the need for roles and purpose to be explained clearly, using summarizing and paraphrasing to ensure that both parties understand each other, and allowing extra time for encounters, so that these may be achieved. Diversity within different groups was highlighted, and we were challenged to identify and address inherent cultural assumptions that we might hold about

different group-members. The need to overtly address both my personal and professional cultural identities, and to critically identify my personal ideology was encouraged. The extensive work I undertook in order to familiarize myself with the new culture in which I would be working was detailed in Appendix One, and I have addressed some of these issues earlier in this Chapter; my Reflexive Account in this thesis is based upon these exercises (Chapter 8.3.3).

This section has summarized the steps I took to effect a culturally sensitive approach to this study.

### **3.3.2 Participant safety**

No distress was likely to occur to participants as a result of taking part in this study. Discussions with community contacts ensured that no coercion was used to involve potential participants. During recruitment and again prior to taking part in the research interview(s), potential participants in all four studies were informed that participation was voluntary and that they may withdraw at any time, without giving the reason. Potential participants in Studies IIIa and IIIb were also advised that withdrawing would have no adverse effect should they wish to attend an EPP course or become a tutor. Murray and Wynne (2001) argue that when respondents speak in a second language they perceive themselves as less confident, happy and intelligent. The potential for these negative self-perceptions should have been minimized by allowing Study III participants a choice of language to be interviewed in, communicating with me through an interpreter as necessary. Should participants have voiced questions or concerns regarding their healthcare, they would have been referred to the Patient Advice Liaison Service (PALS), who are aware of the study. No concern was raised.

### **3.3.3 Researcher safety**

The research interviews undertaken in this study, occurred in participants' homes or workplace, the Research Centre, and at a community centre in an

area of urban deprivation. Before each interview, I ensured that my Director of Studies and at least one other person in the Research Centre knew of my exact whereabouts, and when I was expected to finish. We agreed a time by which I should have finished each interview (typically 1½ hours) and telephoned to confirm my safety.

The Study III research interviews took place in a local community centre attached to a Gurdwara, already used by the participants. I did not access these establishments without the express permission of the individuals responsible for managing them. As my own ethnicity (White) was a potential barrier to being accepted by research participants, steps were taken to ensure that no embarrassment or offence was caused inadvertently. For example, culturally accepted behaviour in these establishments was checked beforehand and followed at all times whilst inside e.g. removing shoes, covering my head and shoulders as appropriate.

#### **3.3.4 Interpreter safety**

No distress was likely to occur to interpreters as a result of taking part in this study. Both of the professionally qualified interpreters with whom I worked in Studies III were familiar with the need for familiarity and confidentiality. The pre-interview meeting ensured that mutual expectations were established. Similarly, post-interview discussions afforded useful opportunities for any pertinent issues to be raised, or for the interpreters to convey information to me that was not possible during the interview. For example, following Study IIIa interviews, the interpreter advised me that participants' spoken Punjabi was not of the highest standard, but they had understood the questions.

### **3.4 Chapter summary**

This Chapter has demonstrated that a qualitative, phenomenological methodology will best meet the research aims of this novel, exploratory study, from both epistemological and pragmatic viewpoints. A small number of

interviews with non-minority and South Asian EPP tutors, and South Asian community-members, conducted with an interpreter as necessary, were therefore conducted. These are detailed in the next four Chapters.

# Chapter Four: Study I

## "We're not fully aware of their cultural needs"

### *White tutor interviews*

#### Chapter Contents

##### 4.1 Study I objective

##### 4.2 Participants and data-collection

##### 4.3 Analysis

##### 4.4 Findings

##### 4.5 Discussion

**Please see Appendix 5.1 for a copy of the following paper, which arose from Study I:**

Hipwell A., Turner A., and Barlow J. (2008). 'We're not fully aware of their cultural needs': tutors' experiences of delivering the Expert Patients Programme to South Asian attendees. *Diversity in Health and Social Care*, 5: 281 – 290.

#### 4.1 Study I objective

The previous Chapters have showed that the already substantial health inequalities experienced by some people from ME backgrounds in the UK, could potentially become exacerbated with the introduction of the EPP, if issues around culture are overlooked. Interview techniques were considered most appropriate to identify any such cross-cultural issue that may have emerged during EPP's delivery to people from ME backgrounds. At the time of the study, the national implementation of EPP was at an early stage, with courses only available in English, and strong anecdotal evidence suggesting

that the dominant mode of delivery was by White tutors. Thus it was important to capture their views, as the majority of ME attendees would be trained by White tutors. When data-collection commenced in the focus-area of Coventry, the specific ethnicity of participants in later studies had yet to be determined. Noting that no-one from a South Asian background had attended the local pilot, it was, however, highly probable that South Asian participants would be sampled. Every tutor who had delivered EPP to a South Asian attendee, was White.

The objective of Study I was to:

**describe non-minority tutors' experiences of delivering EPP courses that have included attendees from South Asian backgrounds.**

It was anticipated that interviews might discern any cultural issues that had arisen during EPP courses attended by South Asian people. This may, in turn, identify potential barriers to their understanding, continued attendance and potential to perform self-management behaviours.

## **4.2 Participants and Data-collection**

### **4.2.1 Participants**

All five EPP tutors who had experience of delivering English language EPP courses that included one or more South Asian attendee were purposively sampled (as is usual for IPA; Willig, 2001; Reid, Flowers and Larkin, 2005; Osborn, 2005; Smith et al., 2009), via Coventry PCT's EPP co-ordinator<sup>4</sup>. The co-ordinator identified South Asian attendees from self-completed demographic data that are collected routinely from every attendee. I telephoned the five tutors who had delivered the relevant courses, giving them a brief overview of the study's aims, and, with their consent, sent an information pack (please see Appendix 2.3, 2.4 and 2.5). This contained an outline of the study, an informed consent

<sup>4</sup> The design decision that the study was conducted locally, was driven by this as a pre-existing funding requirement of the studentship.

sheet, and a demographic data-collection form. Every tutor who was invited to participate in the study, agreed, giving fully informed consent.

Participants were aged 47–71 years, three are female, and their LTHCs include neurological, autoimmune and musculoskeletal conditions. Study I participants are not from ME backgrounds themselves, but are White, reflecting the national demographic of tutors' ethnicities at the time of the study. Three tutors had each delivered a course that had been attended by one South Asian person, one tutor had delivered a course with two South Asian attendees and another had delivered a course with three attendees from South Asian backgrounds.

#### **4.2.2 Data collection**

Qualitative data were collected in face-to-face, semi-structured interviews with each participant. The interview schedule explored tutors' experiences of EPP delivery generally, and of tutoring South Asian attendees specifically (see Appendix Two). It was developed using my supervisory team's expertise in tutor interviews, as an adjunct to the published literature outlined in Chapter Two. Questions for the last section were developed from the extensive fieldwork that I had undertaken (see Appendix One for a summary) and in further consultation with the EPP co-ordinator and my supervisors. Piloting of the schedule was impracticable given the already highly restricted participant population. Indeed, the inherently flexible nature of semi-structured interviews permits questions to be adjusted, should the need arise. The EPP co-ordinator checked the perceived suitability of the interview schedule, and confirmed its likely appropriateness for use with the identified tutors.

Interviews took place in the location of participants' preference; three took place at the University Research Centre, one in a private room at the participant's workplace, and one at the participant's home. Interviews were digitally recorded with the express permission of each participant, then

transcribed verbatim and line-numbered prior to analysis. Coventry University Ethical Committee approval was obtained prior to commencement of the study (please see Appendix Three).

### 4.3 Analysis

IPA is a flexible approach that permits adaptation to an individual study's requirements, rather than a prescriptive methodology. No single formula exists as to how to perform IPA, although good psychological work encompasses different levels of analysis (Osborn, 2005; Smith et al., 2009). I now describe my approach to analysis.

My descriptive level of analysis started with me identifying examples of 'what it is like' from the participants' accounts in the text (Larkin, Watts and Clifton, 2006), annotating my first descriptions of the participant's experiences on the transcript. Next, during interpretative analysis, I examined these descriptions and the transcript for alternative explanations and understandings, using more psychological and theoretical concepts and abstractions, as I attempted to understand participants' 'sense-making' (Larkin et al., 2006) of their experiences. This second order analysis allowed participants' data and my interpretations to be questioned critically for alternative meanings or understandings (Smith et al., 1999), again annotating the transcript with my thoughts and ideas. Caution was exercised to ensure that the interpretative nature of this process did not cause me to lose sight of participants' own words. Finally, I sought connections between participants' data and my interpretations, identifying clusters that were collated into themes of related topics (Eatough and Smith, 2006; Smith et al., 1999).

This cyclical process was repeated for each transcript, with newly emergent themes tested against previous transcripts and current themes. Space limitations preclude detailed reporting of all levels of analysis on all participants' data.



## 4.4 Findings

**Table 4.1: Major themes and Subthemes arising from Study I analysis**

Major themes	Subthemes
<b>Perceived Needs</b>	<i>Tutors' Training Needs</i>
	<i>South Asian Attendees' Perceived Needs</i>
<b>Integration vs. Segregation</b>	<i>Beliefs and Knowledge</i>
	<i>Interpreters</i>

Table 4.1, above, shows the four subthemes that my analysis identified, organised into two major themes. Themes contain examples of participants' cross-cultural experiences and understanding around EPP delivery to attendees from ME backgrounds. Themes are not mutually exclusive, but overlap and contain contradictions, reflecting the complexity of the tutoring situation within its wider socio-cultural context.

In this section, I present examples of the participants' words, to support my identification of the themes, and my interpretations of these. However, I acknowledge that alternative interpretations exist. In order to protect participants' identities, pseudonyms are used throughout this Chapter.

### 4.4.1 Perceived needs

I now examine 'Tutors' training needs' and 'South Asian attendees' perceived needs', which constituted the first major theme of 'Perceived needs', as shown in Table 4.2.

**Table 4.2: 1<sup>st</sup> Major Theme and Subthemes arising from Study I analysis**

Major themes	Subthemes
<b>Perceived Needs</b>	<i>Tutors' Training Needs</i>
	<i>South Asian Attendees' Perceived Needs</i>

### **Tutors' Training Needs**

My analysis next recognized that 'Tutors' Training Needs' were explicitly identified by some participants themselves. Of great interest in the present study, four participants disclosed their need for cultural competence (CC) training. For example, the following quote demonstrates Jane's wish to avoid inadvertently offending South Asian attendees:

***I think that we're not fully aware of their cultural needs. (Pause) ah, and I think it would be helpful to be more aware. Erm, and not find out when you put your foot in it and have done something you shouldn't. (Jane)***

The first sentence suggests that while Jane considered herself to have some awareness of South Asian EPP attendees' cultural needs, she also recognised a knowledge deficit. Jane understood that improved cultural awareness may assist with tutoring South Asian attendees. Using the second person, perhaps to deflect personal culpability, this quote infers that Jane may already have experienced a negative outcome of an unintentional cultural blunder. Jane also implied that she wished to avoid such mistakes when dealing with South Asian attendees.

However, one participant, based on her positive personal experience of dealing with English-speaking South Asian attendees, asserted that delivery of EPP in English does not present a barrier 'for anybody':

***And these are people who have an understanding when it comes to language, you know, English, plus a second tongue, I mean it's only people from this country who have only have one language! . . . And I***

***don't see a lack of understanding when it comes to background language. For anybody. (Lorraine)***

Lorraine's perceived success at tutoring bilingual English-speaking South Asian people is encouraging at face value. However, I interpret her view that people from other cultures are all bilingual, as demonstrating a fundamental misunderstanding of the broader difficulties that are potentially faced by English-speaking South Asian EPP attendees. Training in CC may serve to address this need, and so further advance Lorraine's tutoring skills when delivering English-language EPPs to multi-ethnic attendees. As tutors do not presently receive any CC training, and cannot therefore be expected to possess cross-cultural insight, this is not intended as a criticism, merely a salient observation of a 'tutor need' that my interpretative analysis has identified.

### **South Asian attendees' perceived needs**

Participants' experiences of dealing with EPP attendees from South Asian backgrounds had given them some insight into the specific areas of EPP where cultural needs may differ between South Asian and other EPP attendees. However, tutors expressed some uncertainty regarding which issues might require cultural tailoring to be more appropriate; for example:

***The religious background . . . Um, types of food that they eat, you know? You know, the things that are acceptable, things that aren't [pause] do they object to sitting next to lady, or a lady to a man that's not of their own culture? (Jane)***

Jane understood that EPP attendees from South Asian backgrounds may have culturally specific needs in the areas of religion, food and gender issues. This indicates that Jane was contemplating the cultural appropriateness of the course's content for South Asian attendees (e.g. the food and nutrition section), based on her tutoring experience. She was also considering the cross-cultural pragmatics and perceptions of a South Asian person physically attending the course (e.g. gender issues influencing seating arrangements). However, Jane's

question may demonstrate her uncertainty as to the precise circumstances under which these culturally specific issues might arise.

In contrast, other participants considered that South Asian attendees require neither different treatment, nor cultural modification of the intervention:

***I don't know – I'm just, I can't see how it can differ really. I mean we're all human beings, we've all got health problems, we're all gonna get affected similar . . . so I can't see how you can treat them any different, or the course itself, should be any different. (Jack)***

Interpretatively, this shows that Jack felt that the existential nature of living with a LTHC, complemented by the inclusive course structure, overcame any cultural differences. He did not perceive that EPP attendees from South Asian backgrounds had particular needs, or that the course required adaptation.

**Perceived Needs summary**

I combined these two subthemes into the major theme of **'Perceived Needs'**. Whilst many of the participants understood their needs as tutors, mainly concerning training, my interpretative analysis identified a lack of understanding in others, regarding their needs when delivering to ME EPP attendees.

**4.4.2 Integration versus segregation**

**Table 4.3: 2<sup>nd</sup> Major Theme and Subthemes arising from Study I analysis**

Major themes	Subthemes
<b><i>Integration vs. Segregation</i></b>	<i>Beliefs and Knowledge</i>
	<i>Interpreters</i>

The final major theme, 'Integration versus Segregation', arose from the subthemes of 'Beliefs and knowledge' and 'Interpreters'.

### **Beliefs and knowledge**

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My penultimate subtheme, 'Beliefs and knowledge', emerged as an interesting and unexpected consideration of Jane's socio-political position on multi-culturalism in the EPP context and beyond, in the first interview that I undertook. The following quotation shows that Jane knew that whilst ethnicity-specific courses might actually increase attendance among people from South Asian backgrounds, she believed it was an easy option to offer separate EPP courses by ethnicity:

***I'm torn. (Pause) I think it might be a way of actually getting them there and, and and showing them the course but (pause) when you live in a multi-cultural society is that the way we want to go? And I would question whether we do actually need to put on a separate course? ...  
I think in a way, putting on a separate course is taking the easy way out... Because it's easy to just go and say 'Right, this is all geared towards you, we're gonna ignore that we live in a multi-cultural society'. (Jane)***

This shows Jane understood that facilitating more South Asian people's access to EPP may be achievable through ethnicity-specific courses. However, as she tried to make sense of the wider implications of this, her rhetorical questions suggest ambivalence to the idea. This tension between Jane's multi-cultural ideology, and the perceived benefit to potential attendees, is resolved by her assertion that this relatively 'easy' small-scale solution in the EPP context overlooks broader societal issues around it. Jane, after the recording equipment was switched off, said she considered single-ethnicity courses to constitute 'state-sponsored ethnic segregation' (her permission was sought to use this quote). Her emphatic words reflect Jane's resolute opposition to ethnicity-specific courses, regarding them as highly undesirable.

Similarly, another participant's beliefs and knowledge around the cultural context of EPP delivery, acknowledged that single-ethnicity courses might increase attendance among people from South Asian backgrounds in the short-term:

***My own wish would be that ultimately one could run integrated courses, because I do actually think it's enriching for everybody and. . . I mean it is a bond isn't it, to have a health issue in common? And I suppose I would just like to feel that the course is, as well as benefiting people with their health, could actually help break down barriers between people as well . . . I think one should do anything one can to encourage people and I think that if that means special modules, that would be fine, but I would like to see that as a means to an end rather than an end in itself.***

**(Stephanie)**

This quotation demonstrates Stephanie understood that people's collective experiences of living with LTHCs override cultural differences in the EPP setting. There was again a tension between the participant's personal ideology and social understanding as she tried to make sense of what ethnicity-specific and generic courses mean to her. However, unlike Jane, Stephanie clearly viewed mixed-ethnicity EPPs as having the potential to perform a function beyond health education, in the broader societal context of cultural integration. Her final sentence in this extract concludes by advocating the provision of ethnicity-specific EPP sessions to South Asian groups to boost numbers, but considers them to be an unsophisticated interim solution that overlooks the bigger picture in which EPP sits.

My analysis also identified Jim's concerns about delivering ethnicity-specific Courses. Unlike Jane and Stephanie, he considers that tutors from South Asian backgrounds should deliver the Courses:

***You can't learn their thousands of years of their way of life and their social levels and all the, all the things that are involved in that . . . As well as, they've got to give out the course, because . . . it's difficult to read***

**people who are not of the same ethnic group . . . their psychological reactions you know? (Jim)**

This extract reveals the participant's insightfulness into the complexities of ME cultures' long histories and social structures, which he did not believe training could address. Interestingly, Jim's perception that different nuances in non-verbal cues precluded him from tutoring South Asian groups, led him to advocate ethnicity-specific EPP courses and tutors. His assertion that tutors and attendees should be from the same ethnicity, confirmed Jim's position that cultural differences are intractable, in the EPP context.

Lorraine's 'beliefs and knowledge' about the appropriateness of ethnicity-specific EPPs, differed dramatically. For example:

***I think, this, this fear that the minority groups are not being approached or contacted sufficiently, I think it could be, very easily be a false fear. I feel these are people who are more likely to have the necessary support anyway and don't need outsiders coming in and offering them support that they've already got, you know! (Laughs) ... I think it could equally be that these are people who are perfectly capable of, you know, achieving everything they want without any need for additional support or whatever. (Lorraine)***

Whilst examining the socio-political underpinnings underlying the low South Asian attendance rates on EPP, Lorraine displayed a somewhat stereotypical understanding of ME cultures as collectivist and not requiring 'outsiders' help. However, based on her positive experience of delivering EPP to South Asian attendees, this does, of course, make sense. Her perception that ME groups are all self-sufficient in terms of social support structures for members with LTHCs, thus precluding the need for EPP, also fits into this belief system. The distinctive perspective from which Lorraine understood her world, again provided an enlightening contrast to other participants' views, so contributing rich, valuable additions to this study.

## Interpreters

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The use of interpreters for non-English speakers attending multi-ethnic courses arose during the first interview and was pursued with other tutors in subsequent interviews. Participants used their experiences of tutoring South Asian attendees to consider what this would mean to them – again revealing disparate and contentious views.

The following excerpts highlight that Lorraine did not consider the use of interpreters necessary, while Jack understood that they may help some attendees:

***I think I'd be sorry to feel there was a need for it. Erm, I'd like to know why it's being considered... I can't see a need for it at the moment, I'm not aware of it at the moment. I'd like to know if there is a need for it? I'd like to know why it's being suggested? (Lorraine)***

\* \* \*

***Well if there is a need because of language, then yes! (Jack)***

The expression of regret in the first quote demonstrates that Lorraine viewed interpreters as indicative of some kind of failing. Her somewhat derisory series of questions suggests resistance to the idea, based upon her previous assertion that everyone speaks English. In sharp contrast, Jack would be prepared to work with interpreters if attendees' language requirements necessitated it, understanding that it would enable non-English speakers to attend the EPP.

In the following extract, Jane clearly articulated the practicalities of working with interpreters in multi-ethnic EPPs. Firstly, she talked about the attributes and training that an interpreter would require, then how it would impact upon her running a group:

***... it would help if the interpreter had a long-term condition ... if you'd got one person who needed an interpreter, then perhaps the interpreter***



***could sit next to them or behind them, so they're there actually talking at the same time . . . when you get the feedback sessions, you'd have to give the interpreter time to speak. There's ways of doing it I'm sure!***

**(Jane)**

This participant was aware that the interpreter would effectively become a 'tutor by proxy' to the non-English speaker, and would therefore have a critical role in the success of the EPP for that individual. This was reflected in her belief that the interpreter would ideally be trained about the course and have a LTHC him/herself. Considering the impact that the presence of the interpreter would have on the group, Jane understood that additional time may be required to facilitate the translation process, especially in the group feedback sessions.

### **Integration vs. segregation summary**

I combined these two subthemes into a major theme that considers participants' understandings of the relevant merits around 'Integration versus segregation' of multi-ethnic or ethnicity-specific EPP courses. It is clear that participants' highly divergent beliefs and knowledge about the broader social and cultural context in which EPP sits, directly affect their views around the use of interpreters, should they be required for non-English speaking attendees wishing to attend an English-language course. Thus, the complexity of this issue is highlighted.

## **4.5 Discussion**

The objective of this study was to “describe non-minority tutors’ experiences of delivering EPP courses that have included attendees from South Asian backgrounds”. This objective was met by conducting five interviews with White EPP tutors who had delivered Courses to South Asian participants. It should be noted that the results of this exploratory study cannot be generalised to other White EPP tutors; as this was never an aim, it is not considered a flaw. I again accept the Findings represent my own interpretations of the data; alternatives may exist.

#### 4.5.1 Discussion of Results

Tutors had experienced neither specific nor general problems when delivering EPP courses to multi-ethnic groups of attendees, presenting an encouraging picture of cross-cultural EPP delivery experiences. This research identified tutors' divergent training needs and their sometimes opposing perceptions of South Asian EPP attendees' culturally-specific needs, and highlights the complexities of delivering both ethnicity-specific and multi-ethnic health interventions, such as the EPP. These findings may, however, reflect the small numbers of South Asian attendees that participants had delivered EPP to, and the fact that those attendees were all English-speakers.

A need for cultural competence training for EPP tutors was clearly identified. It should be noted that volunteer tutors are not paid staff. They do not routinely receive such training, are not required to do so, and thus cannot be expected to have cultural expertise. This finding is not, therefore, intended as a criticism of the tutors. Indeed, cultural training is widely advocated elsewhere for health workers, for example for medical students (Godkin and Savageau, 2001), nurses (Wilson, 2004), counselling psychologists (Vera and Speight, 2003) and care workers (Papadopoulos et al., 2004). While the process and content of EPP courses are fixed, enhancing tutors' confidence in dealing with multi-ethnic groups through cultural competence training may promote a stronger therapeutic alliance between the tutor and attendees, which has been shown to be beneficial in other group psychological interventions (Yalom, 2005). However, as Papadopoulos et al. (2004) highlighted, mandatory cultural competence training may lead to ambivalence if participants are made to feel inadequate or guilty. Ideally, involvement of tutors in planning the training may be beneficial.

The participants' suggestion that any culturally tailored courses should consider religious influences, gender issues and dietary differences was noteworthy, as no participant reported these factors as problematic while tutoring South Asian

attendees. This dichotomy between experience and belief may reflect either tutors' cultural stereotypes, or alternatively, that the English-speaking South Asian attendees they had delivered EPP to may be acculturated into Western society. It is also entirely possible that South Asian attendees had experienced cultural issues, but had simply not voiced them to the tutors, who were therefore unaware of their concerns. An alternative explanation for this finding, is that tutors did not want to admit that they had experienced culturally related problems with South Asian attendees, perhaps feeling threatened by admitting this, or afraid of being labelled as racist, thus representing a response bias; I return to this later. A claimed inability to perceive differences, adopting a 'colour-blind' perspective, and the avoidance of discussing issues around ethnicity and cultural diversity, can evoke anxiety amongst White people (Wilson, 2004). However, Johnson and Jones (2003) encourage healthcare providers and workers to acknowledge both their own cultural identity and spirituality, and that of their clients, in order to embrace complexity and diversity.

The issue of ethnicity-specific versus multi-ethnic EPP courses is highly complex. One argument that tutors proposed is that ethnicity-specific EPPs, delivered by trained tutors from the same cultural and linguistic background as the attendees, would encourage more South Asian people to attend. However, given the recognised difficulty around recruitment and retention of South Asian attendees and tutors, this raises pragmatic concerns. Same-ethnicity tutors in the Griffiths et al. (2005) study did not resolve issues of attrition.

Other participants were concerned that ethnicity-specific EPPs could exacerbate ethnic divisions, appearing to propose multi-ethnic EPP courses as a vehicle for achieving small-scale, short-term, cultural integration. While this was certainly never a primary concern of self-management educational interventions, this wider social implication is an interesting viewpoint. Improving accessibility to health education for people from ME backgrounds is, however,

recognised (DoH, 2004, 2005, 2006; WHO, 2005) as potentially contributing to reducing health inequalities, which tutors acknowledged. Bandura acknowledged that health outcomes have traditionally had a somewhat narrow definition, and that the social importance of interventions should be evaluated, in addition to the usual outputs.

Tutors were mostly in favour of employing interpreters for non-English speakers in multi-ethnicity English-language courses. They felt that, ideally, interpreters should themselves be trained South Asian EPP tutors; however, recruitment may be problematic given the current low attendance levels by South Asian people. Raval and Smith (2003) address the complexities that are raised by working with interpreters in a therapeutic context. For example, they argued that the presence of an interpreter changed the dynamic of the alliance between the therapist and service-user, altered power differentials and led to role ambiguity for both the therapist and the interpreter. Thus, in the EPP context, it appears plausible that an interpreter's presence would fundamentally alter the course delivery mode away from the tutors, and onto the interpreter. Similarly, Raval and Smith's finding that interventions became simplified would require monitoring.

Based on her positive experiences, one participant, however, did not consider ethnicity-specific EPPs, or using interpreters on integrated courses necessary, seeming somewhat defensive to these suggestions. This highlights the need to ensure that all tutors are fully trained and informed of the reasoning behind any decision to proceed with ethnicity-specific EPPs or employing interpreters (or CC training, as previously mentioned).

Greenhalgh et al. (2005) proposed that minimal differences exist between South Asian and White patients in certain respects, and suggested that a patient's health literacy may be more important than 'culture' in explaining

health beliefs. These views were strongly supported by some participants in the present study, who believed that the shared illness experiences overcame ethnic or cultural differences. Similarly, Turner et al. (2007) found that Punjabi and Hindi EPP attendees were reassured that the universality of the LTHC experience (for example, isolation and depression) was being recognised across cultures.

Ong et al.'s (2002) findings that Western ideals of shared decision making and patient autonomy differ from traditional Asian cultural and religious attitudes, is not supported here. This may be because of the small numbers of acculturated South Asian attendees whom the tutors had encountered. People who self-refer to attend self-management interventions may differ from the general population, for example in terms of autonomy and motivation. Further research with EPP tutors may reveal divergent experiences of delivering to South Asian people living with LTHCs.

#### **4.5.2 Limitations**

This study has several caveats. The low EPP attendance rates of people from South Asian backgrounds meant the White tutors interviewed here had limited experience of delivering EPP to English-speaking South Asian attendees. All the South Asian EPP attendees were, the tutors reported, acculturated ('Anglicised'- Jim; 'westernised' - Jane). Clearly, this will have influenced tutors' experiences and views expressed. Tutors did not raise many issues regarding the cultural appropriateness of EPP in its current format. This limits the usefulness of the results presented here, as White tutors were largely unable to comment on cultural issues in great depth. This does, however, highlight the need for the current research, to demonstrate how White tutors' limited cross-cultural delivery experience may be influencing the EPP from South Asian people's perspectives. This shortcoming will be overcome in the next study, when South Asian tutors will be interviewed.

Another potential limitation is that of socially desirable answering. Given the sensitive nature of the topic, it is possible that participants may have given 'politically correct' responses. However, tutors' right to anonymity was stressed prior to, and throughout the interviews as necessary, to assure participants that they could speak freely. Given the diversity of answers, response bias does not appear to have compromised the current study.

The next study in the larger project addresses South Asian tutors' experiences of delivering the EPP to South Asian attendees. The final phase will explore Punjabi-speaking community-members' perceptions of health self-management both before and then again after they attend the EPP. Collectively, the studies will triangulate data to provide a comprehensive insight into how best to organise EPP courses to encourage maximum recruitment and retention of South Asian attendees. This, in turn, may allow people from South Asian backgrounds to enjoy the same potential benefits from EPP as the mainstream population, thus addressing one small element of ME health inequalities.

#### **4.5.3 Strengths**

The qualitative design has allowed the detailed exploration and identification of new and complex material. The semi-structured interviews allowed issues around interpreters to be raised unprompted by a participant and subsequently investigated with other participants. This Study has highlighted the need for Cultural Competence training for EPP tutors, who, as volunteers, are not routinely given this. The tutors interviewed here believed that culturally tailored EPP courses might better meet the needs of ethnically diverse attendees. The highly complex issues around delivering ethnicity-specific versus multi-ethnic courses were highlighted, exposing sharp contrasts between different participants' highly nuanced accounts. Believed to be the first published research that has examined White EPP tutors' cross-cultural delivery

experiences with South Asian attendees, the findings represent novel contributions to knowledge.

#### **4.6 Chapter Four Summary**

Study I identified participants' encouragingly positive cross-cultural EPP delivery experiences. Tutors' own perceived needs in terms of training requirements, particularly cultural competence training, and their perceptions of South Asian attendees' needs have been highlighted. The tutors' personal understandings about ethnicity-specific EPP courses for people from South Asian backgrounds, and the perceived appropriateness of delivering EPP with interpreters, have also been addressed.

This Chapter has shown that these often complex issues raised by the White tutors require more detailed exploration with South Asian tutors, in order to gain comprehension of their perspectives. This will capture exclusive insight into their experiences of delivering EPP to South Asian attendees that could facilitate the development of proposals for improvements to ensure these groups are able to enjoy the potential benefits of EPP.

# Chapter Five: Study II

## *"What about the people who can't read?"*

### *South Asian tutor interviews*

#### Chapter Contents

##### 5.1 Study II objective

##### 5.2 Participants and data-collection

##### 5.3 Analysis

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##### 5.5 Discussion

##### 5.6 Chapter Five Summary

#### 5.1 Study II objective

The previous chapter described issues around delivering EPP to South Asian attendees that had arisen for non-minority White EPP tutors, identifying their perceptions of South Asian attendees' needs, and highlighting tutors' need for cultural competence training. Additionally, tutors' understandings around the complexity of cross-cultural course delivery were illustrated. By conducting interviews with EPP tutors who are themselves from South Asian backgrounds, these findings may, therefore, be further illuminated from the 'insider's', South Asian, perspective. Studies I and II can be considered 'multi-perspectival' (Clare, 2002 in Smith, 2009) as they explore the phenomenon of delivering EPP to South Asian attendees, from the perspectives of both White and South Asian tutors. This is considered a 'bolder design' by Smith (pg.52, 2009) for the additional dimension that is brought to the phenomenon under investigation.



Study II's objective was:

**from the perspective of tutors from South Asian backgrounds,  
describe the experiences of delivering EPP courses that have  
included attendees from South Asian backgrounds.**

## **5.2 Participants and Data-collection**

### **5.2.1 Participants**

The EPP Co-ordinator had previously identified that the South Asian communities were particularly poorly represented on EPP courses that had been delivered during the pilot phase of EPP's implementation, confirming Kennedy et al.'s (2004; 2007) assertions that particular attention needed to be paid to such groups. It was therefore decided to interview the three South Asian tutors who had delivered EPP to South Asian attendees, about their experiences, to identify any potential issues that they had encountered, which might present a barrier for South Asian people attending the course. All three participants were purposively sampled (as is usual for IPA; Willig, 2001; Reid, Flowers and Larkin, 2005; Osborn, 2005; Smith et al., 2009) for their experience of delivering an EPP course that had included a South Asian attendee, in any language. The EPP BME Lead, who was newly in post at the start of Study II, identified the South Asian tutors who had delivered the relevant courses. I telephoned the tutors, giving them a brief overview of the study's aims, and, with their consent, sent an information pack. This contained an outline of the study, an informed consent sheet, and a demographic data-collection form (please see Appendix Two). Every tutor who was invited to participate in the study, agreed, giving fully informed consent.

Aged 43–68 years, all three participants were Punjabi Sikh Indian women; their LTHCs included cancer, RA and Type II diabetes. One tutor had delivered one Punjabi-language Course, another had delivered an English-language Course to White attendees and a Punjabi-language EPP to South Asians, whilst one

participant had delivered one English-language and two Punjabi courses, all to South Asian attendees.

### **5.2.2 Data collection**

Qualitative data were collected in face-to-face, semi-structured interviews with each participant, in English. The interview schedule followed the same format as in Study I, exploring participants' experiences of tutoring South Asian attendees (see Appendix 2.6 for semi-structured interview schedule). The EPP BME Lead checked and confirmed the likely appropriateness of the interview schedule for use with the identified participants.

Interviews were conducted in the location of participants' preference; one took place at the University Research Centre, one at the participant's workplace, and one in the participant's home. Interviews were conducted in English and digitally recorded with the express permission of each participant, then transcribed verbatim and line-numbered prior to analysis. Coventry University Ethical Committee approval was obtained before commencement of the study (please see Appendix Two).

### **5.3 Analysis**

My analysis followed the IPA approach as in Study I (please see Chapter 4.3), encompassing descriptive, interpretative and phenomenological levels of analysis. This cyclical process was repeated for each transcript, with newly emergent themes tested against previous transcripts and current themes.

### **5.4 Findings**

As Table 5.1, shows the two major themes comprising five subthemes that were identified. Themes are not mutually exclusive, but overlap and contain

contradictions, reflecting the complexity of EPP delivery within its wider socio-cultural context.

**Table 5.1: Major themes and Subthemes arising from Study II analysis**

Major themes	Subthemes
<b>Barriers</b>	<i>Barriers to South Asians' EPP Attendance</i>
	<i>Barriers to South Asians' EPP Comprehension</i>
	<i>Barriers to South Asians' Self-management</i>
<b>Facilitators</b>	<i>Attendee characteristics</i>
	<i>Access facilitators</i>

These will each now be described and interpreted in turn, with quotations to support my analysis. I present extracts of data to support my analysis, however these are my interpretations and I accept that others may exist. In order to protect participants' identities, pseudonyms are used throughout.

#### 5.4.1 Barriers to South Asian attendance, engagement and Self-management

**Table 5.2: 1<sup>st</sup> Major Theme and Subthemes arising from Study II analysis**

Major theme	Subthemes
<b>Barriers</b>	<i>Barriers to South Asians' EPP Attendance</i>
	<i>Barriers to South Asians' EPP Comprehension</i>
	<i>Barriers to South Asians' Self-management</i>

The participants' experiences of delivering the EPP to South Asian attendees in Punjabi, English, and other languages, revealed seemingly profound barriers to South Asian people attending, engaging and understanding parts of the course's

concepts, content and its delivery mode, and also in performing self-management behaviours.

### **Barriers to South Asians EPP attendance**

**Lack of EPP recognition:** Sukhpreet identified the most significant barrier to BME attendance on EPP as a straightforward lack of awareness about it in these communities. She proposed that that this could be addressed by placing an information stand at the appropriate community-centres, in order to raise EPP's profile amongst these groups.

***Sukhpreet: I think EPP still needs a lot of awareness in the ethnic minority, EPP, not many people know.***

***AH: Really? How might that work, what sort of publicity?***

***Sukhpreet: I think there should be more sort of awareness in the temples, in the mosques, in the mundirs, the other places when there are big functions going on. ...because they have get together evenings and somebody can put a stall up there and put a little bit about it.***

***AH: I see. A tutor, or someone like [EPP Coordinator]?***

***Sukhpreet: I think [EPP Co-ordinator], or, I think somebody did come one time, [BME Lead], because in Asian people, although the English people stand out really good there, but it's the language again. And er, I think it needs to come up time after time, not only 1 time and then forget about it. If these things are there for a good few years, then they can register and they'll say 'Yeah, there is something going on'.***

Sukhpreet's understanding of the way people of differing ethnicities are perceived is interesting. A White person would be more visibly prominent in these BME environments, and so perhaps generate more attention to the information stand that she was suggesting; another person with the appropriate BME language skills would evidently need to be present, too. Her perception that repeat visits, or perhaps even some permanent fixture, would be beneficial is also noteworthy: she seems to suggest that it may take several years to gain South Asian community-members' full understanding and acceptance of EPP.

**Caste:** When I introduced the notion (raised by Study I participants) that ethnicity-specific EPPs could be perceived as segregational, Sukhpreet highlighted the fine-textured complexity of hierarchical social structure of the Sikh caste system:

**AH:** *I'd be interested actually what you think – one of the ladies that I interviewed before said she was concerned that if the NHS ran different EPPs for different groups, they might get accused of segregating people?*

**Sukhpreet:** *Yes, that's another thing, that's another thing. But I think people do feel comfortable when they're in their own group. ... In my own Sikh community there are different castes... I'm pretty easygoing person, I can adapt in any situation. But then when you go, if you're only on your own and you're placed in a group of other people, you feel lost, don't you?*

**AH:** *Yes, I'm the same!*

**Sukhpreet:** *... I feel, I don't feel comfortable at all. And as I say, even in Sikh religion there are several different castes, you know, upper class and lower class, and it's the job they have been doing back home and then they come here, and 'Oh, I'm higher than that person and I'm higher than this person'.*

**AH:** *And that's still active in Coventry?*

**Sukhpreet:** *Oh yes! It does, it does!*

**AH:** *I see, so even within say, a Punjabi Sikhs' Course?*

**Sukhpreet:** *Yes.*

**AH:** *Would then, would the NHS people – how would they find out who to put on what Course??*

**Sukhpreet:** *They won't at all! I don't know whether it does exist in English people or not, but like in Asian people, especially in Sikh religion, we have people who sweep the road, who does carpentry, joinery, blacksmiths, farmers... All these people you can't marry into these people, but nowadays children don't care whether you're marrying the sweeper's daughter or the farmer's – farmers are supposed to be higher because they feed the nation... They are higher people. And we are, my parents were blacksmiths and my husband's parents were carpenters, joiners, right? ... And blacksmiths are little bit higher than the carpenters, right?*

**AH:** *So within the same caste?*

***Sukhpreet: Yes, within the same! You were not allowed to marry people like that, but nowadays people don't care!***

In this extract, Sukhpreet described how she personally understood that caste may present a barrier to EPP attendance and/or full participation for some Sikh attendees, if they perceived it to be attended by Punjabi Sikh people from a different caste to their own. Whilst Sukhpreet appeared socially adept at transversing the castes, she admitted to having misgivings about being alone amongst people from another caste. She explained her individual understanding about the historical roots of the Sikh caste system, which is functioning in daily Sikh life in Coventry and, therefore, on EPPs attended by Sikhs. This quote highlights that, in addition to the usual demands of the course, Sukhpreet perceived that Sikh EPP attendees also potentially have to contend with the discomfort arising from their being from differing castes. Sukhpreet's admission that she has experienced feelings of caste isolation, suggests that, by extension, so might Sikhs attending EPP if people predominantly from another caste were present, or, indeed, people representing a different layer of the same caste. She did not consider the potential impact of caste differences between a Sikh tutor and attendees, but it seems plausible that the same effect may occur. Whether these issues would deter Sikh attendees from completing the course, or whether they would attend but feel less able to fully engage, perhaps by contributing less, is unclear. However, Sukhpreet understood that although this matter appears imperceptible to those outside the community, it does not present an entirely intractable barrier, given her own social mobility, and her suggestion that the caste system appears to be increasingly flexible. Sukhpreet's final comment suggests that she believes the issue of caste may be less problematic for younger Sikh attendees, or for future generations, who may overlook this tradition. I return to this interesting finding in the discussion.

### **Barriers to South Asians' EPP Comprehension**

The participants all identified numerous potential barriers to South Asian EPP attendees fully understanding and, therefore, engaging in the Punjabi-language courses. Features of the EPP itself that participants considered present

comprehension barriers, will be highlighted first, before addressing socio-demographic barriers faced by some Punjabi Sikh attendees.

### **Course comprehension barriers**

**No Punjabi attendees' Manual:** A prime concern amongst participants was that attendees on Punjabi-language EPPs were given an English-language Course Manual, as no Punjabi translation was available (the Tutor Manual on Punjabi courses, had, however, been translated into Punjabi). In the quote, below, Jangjeet expresses her understanding that the provision of an English-language manual was largely pointless and resource ineffective, given that the Manual and the course are inter-dependant.

***Jangjeet: And then the Manuals aren't in Punjabi either, you see.***

***AH: Oh the Tutor Manual is but the –***

***Jangjeet: The Tutor's Manual is, we need that in Punjabi, because obviously we need that for the set Course, but the, the Course Manual that's given to participants, when we had it, it was in English. So I mean that was a total waste of time... They shouldn't have bothered really. I think that's just such a waste of resources, giving them a Manual that's not going to be any good for them to use. And really for them to have it and for someone else to use it, who hasn't been on the Course, well I don't think it's really gonna do them any good. Because the Manual follows the Course, and really it's there for the participant.***

Jangjeet was evidently angry that although the need for EPP to be translated into Punjabi was recognized, this was not performed comprehensively, rendering it less effective for those attendees who are unable to read English and therefore use the Manual. She appears concerned that without the combination of the course and Manual, attendees would have insufficient information to effectively self-manage. Equally, Jangjeet's suggestion that attendees give the Manual to others who have not attended the Course, means that they also are not receiving the full benefit of EPP as they, too, are not in full possession of the entire programme. She considers the translation that has been done to be a wasteful exercise in terms of the time and resources spent upon it.

Karamdeep was equally concerned that Punjabi attendees who cannot read English do not have access to a course Manual, and described, in the following transcript excerpt, how they responded to this:

**Karamdeep:** *Some participants don't take the Manual, the book, they say 'I'm not ever going to read it, do you want it back?' so I said "all right"! So they give it me back. It's been, I don't think they're even doing it.*

**AH:** *Really? And how do participants react then when you 1st hand them this English manual? What do they say?*

**Karamdeep:** *They say 'I'm not going to understand it', some of them don't take it, some of them take it, they say, 'oh my child can help me' sort of, you know. But some of the exercises, like neck exercises, feet, they find that useful.*

**AH:** *Are there pictures of those?*

**Karamdeep:** *There are some pictures there. So for exercises, and stuff*

Of concern to Karamdeep here, was that EPP attendees were being forced into the paradoxical position of dependence on their children to translate the Manual, in order to understand an intervention which aims to *increase* their self-efficacy – their belief in their **own** ability to perform certain tasks. Conversely, it appears possible family-members' involvement in attendees' self-management might provide them with an understanding that affords an encouraging effect on the attendee. "*I don't think they're even doing it*" indicates that Karamdeep understood there are no strategic-level plans to provide a Punjabi-language Course manual. It is, however, encouraging that some attendees recognised the exercise diagrams as useful, and highlights a potential approach to overcome language barriers through pictorial content, where possible.

**Inappropriate Punjabi translation:** Jangjeet explained that different levels and structures of Punjabi language exist between the spoken and written forms, and identified that the level of Punjabi at which the Tutor Manual had been translated was problematic:



**Jangjeet:** ...actually going back to it, you know how the Punjabi manual is written? You see in Punjabi, when you're reading something, the language is a different grammar to the verbal.

**AH:** The words are in a different order or something?

**Jangjeet:** It's more formal when you're reading it... Whereas when you're talking about it to each other, our use of verbs, nouns, our sentence structures are totally different to the written ones.

**AH:** Oh I didn't know that!

**Jangjeet:** So when we were talking to the Punjabi participants, we were reading from the manual, but it was almost like a newscaster reading the news, because it was very formal. When you're talking to someone you don't talk like that.

Evidently, Jangjeet considers that the formality of the language employed in the translated Tutors Manual was inappropriate. Interpretatively, this may have conveyed a sense of unnaturalness and impersonality between tutors and attendees, which could alienate them and thus exacerbate this barrier to their comprehension of the Course content. Clearly, if Punjabi attendees could not understand their tutors, this could potentially compound any problem caused by their not having access to a Punjabi course manual, thus severely compromising the likely benefits they would derive from Course attendance.

**Unsuitable use of medical terminology:** Jangjeet further identified that the underlying assumptions contained in EPP's medical content, was beyond some of her Punjabi attendees' comprehension:

**Jangjeet:** And some of the ...types of illnesses and the words ... that were used, they didn't know what it meant! ... They make references to your liver, your heart, your lungs, and they're all very medical terms, and a lot of the old people, when I did that Punjabi Course, they didn't know what we were talking about, when we mentioned the liver, or erm, the lungs. Because the terms that were used were medical terms.

Jangjeet understood that her Punjabi group experienced difficulties in grasping elements of the Course's content that related to certain organ functions, because of the expressions used. This important finding indicates that, in

addition to addressing the level of Punjabi, the terminology used during the course would benefit from clear lay explanations, to ensure that attendees with even very low levels of health literacy can follow its content. Alternatively, it may be that the cultural norms of health management are so different in South Asian cultures from the Biopsychosocial Model<sup>5</sup> assumptions that these terms represent, that they were simply not recognised by attendees as relevant. I return to this later in this thesis.

In sum, based on their experiences, the participants considered that the level of spoken Punjabi, the absence of an attendees' Punjabi course Manual, combined with the medical terminology that EPP uses, presented a barrier to South Asian attendees' understandings of some of the course's content.

**Conceptual barriers in content:** Participants also raised issues about the conceptual appropriateness of elements of the EPP's content for use with Punjabi Sikh attendees. For example, the Living Wills section aims to empower attendees to address end of life issues in advance, ensuring their families' awareness of their wishes. The following shows that Sukhpreet intensely disliked the Living Wills section, both as an attendee and when training to be a tutor:

**AH: How did that bit [Living Wills] go down, 'cos that part of the Course some people like and some people don't, I gather?**

**Sukhpreet: I personally don't !!! (laughs)**

**AH: What don't you like about it?**

**Sukhpreet: I think it's because people take it in different ways! They think 'Why are they talking about wills and things like that? Are they trying to kill us or what have you', you know?! (Laughs)**

**AH: Oh no!!! They think it's a bit negative?**

**Sukhpreet: It is! It is, this is one thing that they do not like. I didn't [like] it when I was doing it! But when we had, she was excellent you know, she**

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<sup>5</sup> The Biopsychosocial Model of health and illness involves "the interplay of biological, psychological and social factors in people's lives" (Sarafino, 2002; pg480).

***explained it. When I was learning, when I was doing my tutor training, she asked if there was anything you would like to have a little more knowledge about and I said "yeah I'm not very happy about this Living Will and that stage of it". That was Ok and we went over it and it was so clear then! And then I felt better that way, this was one thing I could really explain to them in my own language! That it's nothing to do with people want to kill you and then they're waiting to grab your - whatever you've got!***

***AH: After their money!! (Both laugh) Do you think that's a common misperception then? Do you think, do people?***

***Sukhpreet: It is, it is.***

Sukhpreet's experiences of thinking and talking about end of life issues seem entirely negative, and despite her extra training, and assurances to me, did not appear to feel confident when delivering Living Wills to South Asian attendees. Interpretatively, it seems possible that Sukhpreet blurred the distinction between her own and her attendees' perceptions of Living Wills; perhaps this reflected a cultural difference about the purpose served by wills, which Sukhpreet transfers to her perception of Living Wills. Clearly if wills have wholly negative connotations throughout Punjabi Sikh culture, the usefulness of this section will be compromised. Sukhpreet would therefore need to counter these cultural taboos, as well as delivering the Living Wills section, highlighting the complexity of cross-cultural delivery. The issue may have been further exacerbated by the high level of translation and no Punjabi translation of the attendee Manual.

Similarly, one of the central constructs of the EPP, Action Planning, appears to have raised concerns for some participants. Essentially, this section of the course requires each attendee to set him/herself a small, achievable, goal, to be completed by the following week. Attendees then report back to the rest of the group, highlighting any difficulties encountered, and how they did/did not overcome them. By attaining these small goals, attendees are encouraged to make a little progress, so fostering a sense of personal achievement that enhances their self-efficacy. However, as Jangjeet described in the following quotation, Punjabi Sikh attendees did not generally grasp this concept:

***Jangjeet: And the other thing that was really hard to put across in the Punjabi Course was the Action Planning... they didn't quite get the hang of... what we were actually wanting them to get out of it... they didn't quite seem to pick up the gist. ... That was really hard... Their perception of Action Planning, they just didn't have an understanding of it. And really what the meaning of the 'Action Plan', what we wanted them to get out of it. Because they still did what they every day.***

Jangjeet's experience of delivering the Action Planning appeared to have left her puzzled at the lack of comprehension displayed by the elderly Punjabi Sikh attendees. This suggests that there is no inherent conceptual issue that is culturally inappropriate. One explanation is that attendees were unfamiliar with setting their own health-related goals, perhaps used to paternalistic healthcare professionals doing this for them. Alternatively, this may have arisen as this section of the course used the English words "Action Plan" on the Punjabi EPP, which would, presumably, have been meaningless to these non-English speakers. This could have been exacerbated by the 'high' Punjabi that was then used to explain what was required, as previously highlighted.

**Inflexibility:** The participants described how they found the scripted nature of the EPP's delivery to be grossly lacking in flexibility. It is a requirement of the licensing agreement that tutors summarise or read from the Tutors Manual, thus ensuring consistency of delivery between tutors and courses. As Jangjeet explained in the following quotations, she felt this rigidity was detrimental to her learning an attendee on the Course, when tutor-training and when delivering as a tutor:

***Jangjeet: Xxx put me onto a Course, and when I went on it I think it was a bit slow to start with. You know how the Course is run, through a certain procedure and it's all Copyright, so tutors can't add things in or take things out? And when I first went there I didn't really see what we were doing.***

***Jangjeet: The tutor course was really good, erm, again I think it's very, erm, rigid, and could do with having some degree of flexibility***

***Jangjeet: I think the Course is not flexible enough to use your intuition, to have an input when you feel you need to.***

**Jangjeet: But because of the constraints of the Course, with it not being flexible enough, I think probably the[Punjabi] participants didn't get as much out of it as I would have like to of seen.**

In these multi-layered accounts of her experiences, Jangjeet presented a cohesive argument that the course's inflexible delivery mode had a detrimental effect on attendees' understandings. Jangjeet's clear personal preference for more flexibility, indicated by her multiple representations of its current rigidity, convey a sense of frustration. Of greatest note is Jangjeet's perception that the Punjabi attendees did not benefit as fully as possible, apparently viewing this inflexibility as a barrier to their engagement with the course.

Karamdeep also described her experience of the rigid course format in terms of the time and number of sessions – 6 x 2 ½ hour sessions – presenting a barrier for one group of older South Asian women with arthritis:

**Karamdeep: And another problem I have faced is that erm, people with long-term conditions, they said that they find it very hard to do the Course in 6 weeks... They cannot concentrate so long, they said 'We want to do the Course in 9 weeks' for shorter periods you see.**

**AH: So not 2½ hours, do it in an hour and a half, or**

**Karamdeep: an hour and a half... Spread it out – 45minutes, have a break, then another 45 minutes. And have it in 9 weeks or whatever. And they said 'We cannot sit and we cannot concentrate for 2½ hours'... that's the feedback I had from one of the taster sessions we did in Gujarati, for women.**

**AH: Yeah. And what age-group were they, was that older –**

**Karamdeep: Older. 65 maybe?... We did the taster session, we started the Course as well, they did it 1 or 2 weeks, then said 'This is too much, we can't do it.' We had to stop the Course... They were not saying... 'we don't want to do the Course', they were saying 'We do want to do the Course, but we do not want to do 2½ hours, because we cannot concentrate'. So that's the main feedback, yes!... they were finding it so hard to understand, why cannot we do it, instead of 6 weeks, to 9 weeks? And we said 'We cannot do that because it's licensed Programme, we cannot change it.... We're not allowed to do that.**

***Because it's licensed, we have to run it the way it is. That was very important, er for them, that they could not do it.***

***AH: Do you know what type of health conditions they had? I'm just thinking –***

***Karamdeep: Arthritis.***

Having conducted a successful introductory session with this group, Karamdeep and the attendees were evidently disappointed that the duration of EPP sessions was the causal factor in its failure, leading attendees to withdraw. The seemingly simple solution that would start to address some of the barriers presented by the complex factors of attendees' age and LTHC proved frustratingly untenable, however, within the confines of EPP's licensing arrangement.

Karamdeep had evidently discovered that the Programme's licensing agreement prevents interpreters from being used when required, perceiving EPP's inflexibility around the use of interpreters as another barrier for non-English speakers:

***Karamdeep: Interpreters are used in court, interpreters are used in health, police. Interpreters in murder case, when someone is setting a sentence according to that, then why – obviously that interpreter is interpreting accurately. If we can trust an interpreter in court cases where someone's getting a life sentence, why cannot then we believe that the same interpreter we are using is delivering [EPP] accurately? That is what I cannot understand... We need to check the capability of that interpreter – have they got experience, are they you registered with the Institute of Linguists, have they done Diploma in Health, do they understand what the Course is about? So that's the background work you do with them! Before you do that, but I cannot understand why we are unable to use interpreters, why did the Department of Health put so much restriction on it when they did the license? ... If they use them in the operating theatre, when someone's going through a big operation, why cannot then we use them to deliver simple messages? Which is already there, so interpreter will be, will have time – it's not on the spot like in court, where you are doing it straight away! You're doing it, you'll have time for preparation and everything!... Clarify it with the tutor and stuff like that! I do not – it's strange – understand that...***

Karamdeep's frustration is almost tangible. She perceived the introduction of trained, professional interpreters to be a workable solution to overcome the language barrier faced by some potential EPP attendees. Indeed, Karamdeep understood that the scripted nature of course-delivery may actually assist interpreters in the EPP context. She appeared affronted that interpreters' professional skills that are recognized in the most critical of situations elsewhere, are apparently dismissed by what Karamdeep perceives as bureaucracy within the EPP, at the expense of marginalised people who could potentially benefit.

### **Socio-demographic comprehension barriers**

**Low educational status:** The extent to which low educational status and illiteracy are prevalent amongst this particular South Asian community emerged during the interviews. In this experiential illustration, Jangjeet demonstrated how she understood many South Asian attendees' illiteracy impacted negatively upon the likely success of EPP:

***Jangjeet: And the other thing with the Asian population, I don't know if this goes for the Chinese, or Bosnians, or the others, but a lot of the Asian older population are actually illiterate. ... So what about the people who can't read? And that's another aspect of Asians for you, whereas on an English Course, everybody can read, near enough, I'm sure. They might have problems with spelling and stuff, but in terms of what you've written, there's a big difference, with like the 60+ who can't read, a lot of them.***

Jangjeet clearly perceived the illiterate South Asian attendees to be disadvantaged in their learning potential, which could ultimately impact on their ability to understand the course. Jangjeet's perception that most English-speakers who attend the course are literate is an interesting observation, but raises the question as to whether the same would be true if disadvantaged White groups were specifically targeted to attend EPP.

**Age:** Whilst describing the difficulties that she experienced when conveying the concept of Action Planning to Punjabi Sikh participants, Jangjeet also

revealed her understanding of a potential reason for the difficulty: attendees' age:

***Jangjeet: And the other thing that was really hard to put across in the Punjabi Course was the Action Planning.... There were a couple of participants that picked it up and understood, but the other participants, who were probably much older, didn't quite get the gist of it from the examples of what we were giving... we had in that second [Punjabi] group, a receptionist from a doctor's surgery – she was really good... the other were 70+ who had chronic illnesses, but their perception of Action Planning, they just didn't have an understanding of it.***

Jangjeet's perception of an age divide in attendees' conceptual understanding is noteworthy. Jangjeet presented an interesting explanation, mentioning the younger, doctor's receptionist DID understand the concept of Action Planning. The fact that she was working strongly suggests that this attendee is also English-speaking, which would have helped her overcome any language barrier. Additionally, she may also be more familiar with the concepts of forward-planning and goal-setting, which are often integral parts of a Western work ethic. It could further be assumed that her professional role would render her health literate. Interpretatively, this may suggest that the generational difference between Punjabi Sikh attendees that Jangjeet has identified, could be explained in terms not only of age, but also English-speaking ability, educational status and, as previously raised, health literacy.

Jangjeet again illuminated the subject, when I asked her if she considered ethnicity, educational status or age to present the most substantial barrier for this Punjabi Sikh group:

***AH: So there's this distinction being made on ethnicity, I wonder if it's actually educational level, or age?!***

***Jangjeet: It's probably both. Educational because they don't understand a lot of the language, and age because they're so set in their ways, you can't change them.***

This conveys Jangjeet's understanding that, in addition to linguistic needs, this subgroup of older Punjabi Sikhs had inflexible attitudes which did not lend themselves to modification through intervention such as the EPP. If her



perception was found to be accurate, this raises interesting questions about the appropriateness of any health/education intervention for this group.

Interpretatively, this somewhat defeatist attitude may suggest that Jangjeet did not identify with her group of attendees (like Lorraine in Study I), perhaps as a result of her own, high level, educational status. It further confirms that engaging tutors of the same ethnicity as EPP attendees, cannot be assumed to provide an automatic understanding of the whole culture's needs, as it overlooks complex interpersonal differences.

### **Barriers to South Asians' Self-management**

Further to participants' perceptions of potential obstacles to South Asian EPP attendees' attending and comprehending the course, they also identified possible barriers to successful implementation of self-management behaviours for those who DID attend and understand the EPP. For example, Jangjeet understood that the older Punjabi-speakers' lack of familiarity with the fundamental concept of structured educational courses may have presented a further barrier for some attendees:

***Jangjeet: I don't think they quite got the gist of what the Course was all about. I think they thought the Course was a social event – 'My friend's coming, I'm going to come and spend time with her, and we're going to talk about...'***

It appears unlikely that attendees would achieve active self-management status if they were unaware of the basis for their enrolment upon the course, and the need to engage with its content. It seems plausible that attendees had not understood any explanation that they may have received about EPP's purpose, and their required participatory role, when they were recruited. It again appears that the inflexible nature of the scripted manual did not permit tutors to provide explanations or reminders about the course's aims and objectives, in order to clarify this and so help attendees engage with the Programme.

Another barrier to Punjabi Sikh attendees successfully performing self-management behaviours that was identified, concerns the conventional gender-role expectations within traditional Punjabi culture:

***Jangjeet: ...And I think in a Punjabi family setting, the woman is always in charge of the food, you won't get men going in there to cook, but they want their food tasting nice, so there's also that constraint... Women aren't allowed to be flexible enough to change the diet, if they want to experiment.***

Jangjeet pointed out that whilst Punjabi men are not physically involved in food preparation, their influence precludes Punjabi women from culinary experimentation around healthier food if the men consider that it negatively affects the food's taste. In a clear reference to the food and nutrition section of EPP, Jangjeet considered that the influence of Punjabi gender-role norms amongst this group may prevent meaningful change, and, therefore, render this section irrelevant. A method of overcoming this potential cultural obstacle is proposed later in this Chapter.

Following on from these specific concerns that Jangjeet had raised, I asked for her overview of the EPP for the Punjabi group:

***AH: Would you say generally, the Course met the needs of the Punjabi group that you –***

***Jangjeet: Some of it, some of it not. Not as thoroughly as my English-speaking Course.***

It is evident that Jangjeet did not consider that the Punjabi-language EPP was as effective for these attendees as was the mainstream course that she delivered, in this brief summary of its perceived success. It follows that for those Punjabis who attended this course but for whom it did not fully meet their needs, it may, therefore, have had impoverished behavioural outcomes.

## Summary

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This section has described the potential barriers to South Asian EPP attendees attending, engaging, understanding, and performing self management behaviours, which participants raised during interviews. The profile of older, uneducated people who are unused to learning, being typical of South Asian EPP attendees in participants' experiences, this section highlighted that these complex issues all intersect on the EPP.

### 5.4.2 Facilitators

**Table 5.3: 2<sup>nd</sup> Major Theme and Subthemes arising from Study II analysis**

Study II Major theme	Subthemes
<b>Facilitators</b>	<i>Attendee characteristics</i>
	<i>Access facilitators</i>

The three participants' experiences of delivering EPP to South Asian attendees had also enabled them to identify factors that they considered would enhance the attendance on and understanding of the course, for people from these backgrounds. The following experiential examples support the tutors' arguments for the need for highly tailored courses to be targeted at very specific sub-groups of particular communities, and the steps that organisers might consider to achieve this.

### Attendee characteristics

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**Religion:** Sukhpreet asserted that recruiting South Asian attendees from the same religious background would facilitate both their participation in EPP and her own delivery experience:

***Sukhpreet: But it would have been better if the Muslim people's group was separate from the Hindus.***

**AH: Oh right. Why do think that is?**

**Sukhpreet: Because if there was any religious issue and the people could not speak up openly. I mean it wasn't that we were sort of trying to (pause) talk down, but there were certain issues that you have to think 'Oh I shouldn't be saying that' you know. And somebody sometimes, you would probably say the Muslims don't do this, the Sikhs don't do that and the Hindus don't! But then you can't, you can't say that.**

**AH: Because it might offend?**

**Sukhpreet: Yes, yes, yes.**

**AH: It sounds like you have to be really careful?**

**Sukhpreet: You have to be really, really careful, you know, you have to choose your words [both laugh]. It's difficult.**

This quote reveals the highly refined subtleties of South Asian inter-cultural relations, which are apparently overlooked when courses are organised around language alone. Sukhpreet does not say why attendees would not speak openly, but, interpretatively, this could be for fear of offending others with differing religious beliefs. Her comment about not 'talk[ing] down' religious issues is interesting, and has differing potential explanations. One interpretative explanation is that Sukhpreet's awareness of attendees' divergent religious sensitivities, may have led to her avoiding directly addressing such issues, again through fear of causing offence. Alternatively, the tutors may have attempted to dismiss any religious issue attendees raised, so as not to be drawn into contentious debate, but in so doing, may have inadvertently patronised attendees. However, the same may be true for EPP courses attended by members of other faiths. The quote conveys a sense of discomfort, or perhaps even tension, between the different attendees whom Sukhpreet was tutoring. It is also evident that treading a very delicate path through this ethical minefield, presented an enormous burden to Sukhpreet. Implicit in this extract, is her realisation that the cultural-specificity of EPP was lacking. Evidently, Sukhpreet believed that single religion courses would prove more effective both for her attendees, and also for herself in terms of ease of delivery, as tutor. It was also Sukhpreet, above, who identified the need to consider the role of attendees'

caste; together, these findings reveal the subtle refinements that would ideally be required to ensure cultural EPP's competence.

**Language:** All three participants agreed that language was a major factor in determining the likely success or failure of EPP with any group, as Sukhpreet succinctly shows here:

**AH: *I wonder, could you identify the main needs of people from the South Asian backgrounds when you've been tutoring? [Pause] Is it information, is it a language issue, is there, what helps most?***

**Sukhpreet: *Language is the biggest issue there.***

Sukhpreet's tutoring experiences with people from South Asian backgrounds led her to understand that language is imperative in this context. Sukhpreet elaborated upon this, highlighting the complexity of delivering multi-lingual courses, and giving an example of an English-language course that she delivered to South Asian attendees, which required her to speak several languages:

**Sukhpreet: *...the 2nd set [of attendees] I had was Gujarati mixed with Muslims and then I had to speak Hindi and some Gujarati.***

**AH: *In that same session?***

**Sukhpreet: *In the same session, and English.***

**AH: *So you'd got at least 3 different languages!***

**Sukhpreet: *Yeah!***

**AH: *And how did that work for you?!***

**Sukhpreet: *Because most of the Course was delivered in English, it was only if people didn't understand you know, and we said if anybody doesn't understand we will try and explain. So people would just put their hand up if they didn't understand and we would explain in Gujarati or Hindi or Punjabi.***

South Asian attendees' inclusion on an English-language EPP suggests the possibility that they may have been more educated than attendees on South Asian language courses. However, the need for Sukhpreet to provide

explanations to this diverse group of English-speaking South Asian attendees, underscores the earlier point that the assumed level of Western health literacy inherent within the Course, is inappropriate for South Asian attendees.

Sukhpreet used her language skills to ensure that all attendees understood the Course's content; however this clearly involved her leaving the scripted English manual, and would have altered the timings of these sessions, in addition to affecting attendees' experiences of the Course. Whilst Sukhpreet does not suggest that she or the attendees had any objection to this, and it evidently provided an effective solution to the issue of attendees' comprehension, it appears less than an ideal situation for all involved.

However, another participant's experience of delivering a course to a group of fellow Punjabis, did not encounter this difficulty:

***Jangjeet: I really enjoyed doing it in Punjabi, because I could, being a Punjabi myself, I could relate to their problems at home, medical problems, social problems, because it was my culture. I could see where they were coming from.***

This extract suggests that Jangjeet was fully able to embrace Punjabi cultural norms in the context of EPP, when delivering in one language, perhaps feeling on the same cultural wavelength as her attendees. It seems likely that this may have been more effective delivery-mode (for tutor and attendees) than the experience Sukhpreet described, above. This suggests that tailored language AND ethnicity-specific EPPs may work better than generic South Asian/language Courses. However, as reported earlier in this Chapter, this does not necessarily guarantee problem-free delivery.

**Single gender groups:** Sukhpreet advocated that courses should be organised around gender, even if not for entire duration of course. The following highlights how and when she believes this could be achieved:

***Sukhpreet: Because not many ladies like to come with men to attend and talk about their problems... There are certain things in the***

***Programme that I could not even talk about – I mean your sex life and it's a little bit mentioned in the manual, that people have, when they've been on long term medication and they can't 'perform'... And then the other partner gets very, very frustrated. I cannot talk about that you know! And I thought my core tutor would take over but [laughs] he didn't say anything about it [both laugh]! And it was something like that you know, I think that you could talk to the ladies comfortably, or men can talk to men. Even if we have a group, like a mixed group, and when we're talking about something like this, if they can ask the ladies to walk out for 10 minutes, have a break or something?***

***AH: Do that bit in different rooms?***

***Sukhpreet: Yes! That's another suggestion I would like to make!***

As neither tutor felt able to address the sensitive section that discusses sexual dysfunction resulting from LTHCs, it appears that it was spontaneously omitted from this course. Perhaps indicative of a particular training need in the tutors concerned, Sukhpreet describes the extreme discomfort she felt when faced with presenting such material to a mixed-gender group, understanding that talking to women would not provoke such anxiety. Her proposal to deliver this material to separate gender groups does not suggest that the topic is intrinsically culturally inappropriate.

**Couples** Paradoxically, in order to overcome the issue of South Asian men purportedly misunderstanding their wives' attempts healthy food provision, Jangjeet advocated targeting Punjabis as couples, when they attend the Temple:

***Jangjeet: Women aren't allowed to be flexible enough to change the diet, if they want to experiment. So that's why you catch them at the Temple, they're there together and then there's an understanding – the husband doesn't think the wife's trying to do something to him!! [Both laugh] When the food doesn't taste as nice! Or he thinks she's just being mean!***

***AH: So you could get the men at the Temple as well, to educate them as well?***

***Jangjeet: Yes, they're there!***

Jangjeet understood the importance of Punjabi men's acquiescence if the nutrition section is to be effective, and had identified that recruiting them with their wives at the Temple and involving them in EPP would achieve this. However, caution would need to be exercised given the previously reported facilitator that some women prefer single-gender courses; this contradiction again confirms the complexity of issues around cultural tailoring, and the need for choices to be offered.

### **Access facilitators**

**Location:** Analysis identified concordance between participants' understandings about how and where Punjabi Sikh people learn about their health. As Jangjeet showed in the following excerpt, older Punjabi Sikhs learn from each other, in their informal social groups at the Gurdwara:

***Jangjeet: I think from the Punjabi point of view, the biggest learning place for them is in their social groups, and I would say that 90% of all the 60+ Punjabi people go to the Temple. They have like, erm, they have these morning functions, where all the ladies go off for this religious thing and then afterwards, we all sit and have a natter! That's the time to catch them!! Cos that's the time they're all talking to each other 'I've been on this Course' and 'I've been doing this' and 'this is the medicine I'm taking for my bad back' and that's where you're learning a lot of stuff as well.***

Interpretatively, this suggests that Punjabi culture embraces the concepts of social learning and peer support, which is encouraging as both are integral to the EPP. Jangjeet understood that this will be useful when targeting the place and timing of culturally-specific recruitment: at the Temple following the religious ceremony. This confirms Sukhpreet's perception, presented earlier in this Chapter, that the lack of recognition of EPP amongst South Asian communities could be addressed by marketing the course at different places of worship.

**Marketing EPP:** In the final facilitator to South Asian people's attendance on and participation in EPP, participants offered proposals about how best to



overcome some of the seemingly profound barriers to EPP's success amongst these communities. For example, Jangeet suggested providing potential attendees with an opportunity to learn about EPP before attending it:

***Jangeet: I think, I think erm, probably I think with the people whose first language isn't English, perhaps we need to educate them first? As to what we actually want them to [get] out of the Course.***

This participant understood that such taster sessions could give those attendees for whom English is not their first language an overview of EPP's aims and objectives, and the concept of self-management. This may overcome the previously-described conceptual issues that a structured educational intervention apparently presented to South Asian people not familiar with learning. Whilst meaningful enhancement of health literacy would likely be beyond the scope of such a session, a brief overview of the terms encountered during the course, within a Western Medical model, might also prove fruitful, in view of findings presented earlier in this Chapter.

In an unexpected finding, Karamdeep identified a popular resource that Punjabi Sikhs use to educate themselves about their health - Indian television channels:

***Karamdeep: ...there's a lot of trend now, people watch a lot of Indian television, urm, some of the yoga scientists come, and they're not saying it because they just plucking it from the air - they have scientific evidence backing it... So they have a laboratory to say this, these exercises, these things are working... And there's scientific, it's proven scientifically, that it works.***

It is apparent from this quotation that Karamdeep considered television to be a reputable source of accurate health information, supported by scientific proof. Interpretatively, Karamdeep appeared keen to stress the scientific validity of the broadcasts, perhaps to convince me of their legitimacy, as an academic. If this belief in TV documentaries is widespread, it seems likely that people from South Asian backgrounds might use Indian television as an additional source of health information. Thus, television's potential as a resource for raising awareness of EPP, including its culturally competent tailoring (when complete), as discussed earlier

in this Chapter, could be highlighted in a documentary. Furthermore, TV advertising of EPP and its benefits could be considered.

## **Summary**

This Theme has drawn together features that, when present, may help South Asian community-members to attend and engage with EPP, and, consequently, perform self-management behaviours. Courses tailored by the religion, language and gender of attendees were advocated, with recruitment strategies to counter the present lack of understanding about EPP proposed.

### **5.5 Discussion**

Study II revealed, from Punjabi Sikh perspectives, potential barriers to South Asian people's EPP attendance, engagement and performance of self-management behaviours, in addition to isolating a number of facilitators that may promote EPP amongst South Asian communities. As detailed description and interpretation of participants' rich accounts is the aim of IPA research, it should be noted that the results of this exploratory study cannot be generalised to other South Asian EPP tutors. Similarly, I again accept the Findings represent my own interpretations of the data; alternatives may exist.

#### **5.5.1 Discussion of Results**

The participants in this study identified numerous difficulties for South Asian people attending and fully participating in EPP, and also obstacles to their engagement in certain self-management behaviours, in the first major theme of *Barriers*, which is discussed now. This outlined the participants' perceptions around South Asian community-members' awareness of EPP, and features of the Course's format and delivery mode that participants understood may have prevented optimum participation and understanding of EPP for these attendees.

The perception of a fundamental lack of awareness about EPP amongst South Asian people is clearly important, given that these groups have been identified as requiring particular attention to avoid exacerbating health inequalities (DoH, 2003a, 2003b). It confirms findings from the national evaluation of EPP's pilot phase, which highlighted that *"only limited progress was made in successfully targeting ethnic minority and socially deprived groups"* (Kennedy, Gately, Rogers, 2004, pg.5). As the EPP BME Lead had only recently been appointed at the time of the interviews, it is perhaps unsurprising that the effects of her work had yet to be felt at community level, and is in no way intended as a criticism of her work. However, the extent to which people in mainstream society knew about EPP's existence at the time of the interviews is unknown, so ascertaining whether the problem was more severe for South Asian groups, as participants perceived, is impossible (and was not an aim of this Study). This finding counters Lorraine, in the previous study, who asserted that *"I think, this, this fear that the minority groups are not being approached or contacted sufficiently, I think it could be, very easily be a false fear..."*.

Revelations from one participant about the Sikh caste system as a potential barrier to Punjabi Sikh attendees continued attendance and participation in EPP are particularly noteworthy. Whilst the issues of culturally-tailored, linguistically-appropriate courses have been addressed previously (Griffiths, Motlib, Azad, et al., 2005), Sukhpreet's response highlighted the naivety of my question. Not only are ethnicity-specific courses absolutely pre-requisite to some Sikhs' attendance on EPP, but Sukhpreet considered that attendees may still face further barriers to engagement, depending on the perceived layer of caste that other attendees are from. However, highly sensitive recruitment may overcome this issue. This finding not only highlights the necessity of a flexible research approach in order to accommodate unexpected disclosures, but also identifies one of the challenges of researching a new area - knowing what to ask!

However, a note of caution warrants introduction here. Given that the Sikh religion arose in response to the perceived restrictive Hindu caste system, and entirely rejects caste, it is entirely possible that this finding reflects one individual's view that is not widespread amongst other Sikhs, in this community or elsewhere. Chandigarh (retrieved 2010) asserts that in the Punjab, caste (*jat* or *zat*) signifies only an ethnic group *gotra* (family, line, sept or class), like the MacDonalds and Montagues, in Britain. Thus, this finding may reflect this participant's subtle differing use of the term 'caste', from my understanding of the word – or may be talking about her perceptions of social class differences. The Sikh caste system as a potential barrier to other areas of healthcare, and therefore a possible contributor to ME health inequalities, therefore warrants further exploration.

Participants described the absence of a Punjabi Course Manual for attendees as a *Comprehension Barrier*. However, it does not appear that the effectiveness of different delivery-modes - with and without the attendees' Manual, in any language - have been evaluated, so its role in attendees' understanding is not known. However, that all EPP attendees on different language courses were not provided with the same basic materials, appears to constitute a clear inequity, and, potentially, a flaw in the quality framework. Similarly, "*South Asian cultures often place more value on a listening relationship with a person who understands them than on written forms of communication*" (Adebajo, Blenkiron and Dieppe, 2004; p. 1322). Yet this itself raises further questions: by Jangjeet's own admission, many Punjabi Sikh attendees were illiterate in any language, so it calls into question how a Punjabi Manual would help such individuals directly, as they would be unable to read it. The issues of low health literacy and educational status amongst the Punjabi Sikh attendees, whom this Study's participants had delivered EPP to, are addressed shortly.

The inappropriately 'high' level of the Punjabi translation of the Tutor Manual, which participants considered to be a comprehension barrier to Punjabi Sikh understanding, has now been addressed. This again reflects a transitional finding of the present study, which occurred during an early stage of the EPP's metamorphosis from pilot phase to mainstream implementation. Whilst no formal evaluation has been conducted on the Punjabi EPP, anecdotal evidence suggests the new translation is a considerable improvement over the original adaptation, preferred by tutors with experience of delivering both versions. User involvement in the development of culturally-tailored educational materials (Adebajo et al., 2004; Greenhalgh, Collard and Begum, 2005; Samanta, Johnson, Guo and Adebajo, 2009) on Punjabi-language EPPs, may have prevented this issue of inappropriately formal translation from occurring initially.

Similarly, participants perceived that the course contained conceptually inappropriate subjects (Living Wills and Action Planning) that presented an obstacle to some Punjabi Sikh attendees' comprehension. These may also have been avoided, had community-members been involved in the planning stage of the Punjabi adaptation (Adebajo et al., 2004; Greenhalgh et al., 2005; Samanta et al., 2009). The potential utility of such user involvement in the EPP context is considered in more depth shortly. It is, however, noteworthy that anecdotal evidence also indicates that Living Wills are unpopular on mainstream EPPs, suggesting that the Punjabi Sikh attendees, whom participants had delivered to, were more similar than different from the White population. Indeed, this section has now been redesigned, and may be omitted.

The need for EPP to be tailored to meet the needs of attendees with low health literacy is confirmed by the present study. It is evident from participants' accounts that some Punjabi Sikh attendees were illiterate (in any language) and had low levels of health literacy, but found the pictorial representations of

exercises to be beneficial. This finding accords with previous studies in low-literacy and low health-literacy groups that have found non-text-dependant education to be appropriate in South Asian groups (e.g. Greenhalgh et al., 2005). Similarly, an Arthritis Research Campaign (**arc**) multidisciplinary group concluded that literacy presents a major problem for significant numbers of patients, who might benefit from materials that use culturally-sensitive pictorial representations (Adebajo, et al., 2004). In the same Editorial, Adebajo et al. (2004) also stressed the importance of working with target communities in developing the most effective health promotion strategy and materials, designing such materials with the user groups and evaluating them in collaborative research involving patients. Samanta, Johnson, Guo and Adebajo (2009), further assert that in order to be meaningful and useful, culturally competent information resources for South Asian people with arthritis should include regular fitness for purpose evaluations by target community-members. Greenhalgh et al.'s (2005) innovative approach to developing health education in South Asian communities resulted in a tailored, culturally competent diabetes education intervention.

Yet this has potential implications beyond the Punjabi Sikh/EPP context: Weinman et al. (2009) recently investigated levels of anatomical knowledge, finding that patient groups and members of the general public lacked rudimentary knowledge of the location of bodily organs, including the heart, liver and lungs. Participants' ethnicities were not given, and the study appears to have taken place with English-speakers. Increased age reduced participants' scores, and increased educational level increased scores. Given the descriptions provided by the present Study's participants, it therefore appears entirely plausible that their concerns around older, illiterate, Punjabi Sikh attendees' lack of comprehension, based on the Course's assumptions of health literacy, are entirely warranted. It is further possible, based on Weinman et al. (2009)'s findings, that the inherent assumptions of health literacy within EPP's content may also be challenging for non-Punjabi Sikh attendees: this requires further investigation.

Together, the findings around the Sikh caste system, the absence of a Punjabi Manual, the overly-formal level of Punjabi, in combination with EPP's assumptions around Punjabi Sikh attendees' literacy and health literacy, offer strong confirmation from a Study I participant: "...we're *not fully aware of their cultural needs*" (Jane). Indeed, in addition to White tutors somewhat lacking in cultural competence, the same also appears true of the course itself. Clearly, should the community-involvement approach be adopted by the EPP-CiC to redesign the Course materials and previously mentioned elements of its content, this may start to address some of the issues raised in the current Study.

Another finding from the present Study that accords with previous research in mainstream groups, is the unpopularity of tutors reading verbatim from the Manual to attendees. Disliked in predominantly White samples, this corroborates Kennedy et al. (2005) and Barlow, Edwards and Turner (2008) findings. Similarly, anecdotal evidence suggests that this feature of EPP is disliked amongst tutors and attendees. Whilst EPP's scripted delivery-mode purportedly adds to the 'quality assurance' of delivery, fulfils licensing requirements, and is sought by NHS commissioning staff, its inflexibility calls into question its fitness for purpose, in this particular setting. The failure to recognise the potential importance of working with interpreters in the EPP context represented further evidence of the Course's lack of cultural competence, with implications for EPP-CiC under The Race Relations (Amendment) Act (Home Office, 2000). Local knowledge, however, suggests that this line has now been softened, with Courses now being delivered for non-English-speakers with an interpreter. However, working with interpreters is highly complex, and has been found to change the communication process, the working alliance, and lead to simplified psychological interventions (Raval and Smith, 2003). The authors proposed that structural inequalities, training and good practice guidelines could, however, help ME service users needing interpreters. How this would change the course for other EPP attendees (for example, in terms of the additional time required to provide an attendee with an interpretation) would also require consideration.

One participant's perception that Punjabi Sikh attendees were unlikely to fully benefit from EPP due their age-related fixed mindset, is not supported elsewhere in the literature. For example, the Coventry University research team have been involved in considerable research with older people in the mainstream population, who have attended EPP/ASMP and, largely, benefitted (e.g. Barlow, Turner and Wright, 1998: mean age 59 years; Buszewicz et al., 2006: mean age 68; Barlow, Turner, Swaby et al., 2009: mean age 65), suggesting that age alone does not inevitably lead to inflexible attitudes that present a barrier for everyone. Whilst this finding may be unique to the group this tutor had delivered EPP to, if it were found in other Punjabi Sikh groups, it could represent a cultural difference between Punjabi Sikh and other older attendees given that the above studies predominantly involved White participants. Alternatively, it perhaps reflects this tutor's experience with this largely uneducated, illiterate group with low levels of health literacy, which contributed to their lack of comprehension - but she attributed it to their age. A number of theoretical explanations exist for this. For example, it is possible that this tutor has committed a 'fundamental attribution error', by assuming that internal causes or dispositions are responsible for others', negative, behaviour ('they are old/like that'), rather than considering the external variables influencing the attendees (Brown, 1995). Alternatively, a 'Stages of Change' approach may suggest that attendees were at a pre-contemplation stage (e.g. Prochaska and DiClemente, 1984, in Sarafino, 2002) of their LTHC experience, and had not yet considered behavioural change, and thus were resistant to the Course's content. Equally, neurobiological evidence supports the view that cognitive performance declines with increasing age (Salthouse, 2009).

Another finding from this Study was that some South Asian attendees fundamentally misunderstood the purpose of EPP, with one tutor understanding that her group regarded it as a social occasion rather than an educational course. The course attendees were an existing social group, meeting for EPP in their usual social place, so this behaviour probably represented their normal



behaviour. Whilst the participant perceived this as a negative feature of attendees' behaviour, perhaps placing additional demands on her during delivery, it may actually represent a positive characteristic of the group, given the recognised role of social learning (Bandura, 2004; Barlow, Bancroft and Turner, 2005; Barlow, Turner and Gilchrist, 2005). Indeed, accepting the universal functional value of efficacy beliefs, Bandura (1999) argued that *"cultural context shapes how efficacy beliefs are developed, the purpose to which they are put, and the social arrangements through which they are best expressed"* (p.35). However, if the attendees were **not** paying attention, clearly the potential effectiveness of the course would be compromised. Local anecdotal evidence supports that working with South Asian groups can present additional challenges in managing informal behaviours such as those that the participant alludes to, suggesting that this informality may constitute a different cultural norm. Similarly, Greenhalgh et al. (2005) described educational group work with South Asians as *"casual (and sometimes frankly chaotic)"* (p.128) and noted that *"There is resistance to formal facilitation and to a pre-set agenda"* (p.128) which appears to resonate with this finding. Yet Barlow Swaby and Turner (2008) also identified that some mainstream attendees do not understand the purpose of EPP, indicating that the Punjabi Sikh attendees were more similar than different from their White counterparts in this respect.

One participant's understanding of Punjabi Sikh traditional gender-roles in relation to managing dietary aspects of LTHCs is interesting, with male concordance apparently pre-requisite to Punjabi Sikh women making dietary changes, in this participant's experience. The extent to which EPP attendees from other ethnicities may have experienced similar gender-role issues within a self-management context, does not yet appear to have been documented. Gender differences in health beliefs have been identified previously. For example, Dickinson and Bhatt (1994) recognized that South Asian women tended to believe (more than men) that health was a matter of luck and that 'people like them' had no time to think about their health, which implies they felt disempowered and disinterested. In the same study, however, male *and* female South Asian respondents overwhelmingly agreed that diet was central

to health, which suggests that male Punjabi Sikh may be open to education about healthy food, as suggested by one participant. The presence of couples as suggested by one participant to overcome gender-role issues may, however, cause discomfort for any participant who preferred single-gender group, again highlighting the need for close consultation with potential attendees on EPP Courses. Griffiths et al. (2005) RCT of EPP with Bangladeshi Muslims recruited single-gender groups, which accords with another participant's understanding that this may reduce anxieties caused by sensitive issues that the Course raises. This supports the Study I participant who demonstrated awareness that gender may be an issue for some South Asian attendees; I return to this in the following chapter. However, there does not appear to be research evidence that confirms whether single-gender courses would be more effective than mixed-gender EPPs, in any cultural group. A number of factors that participants considered would assist South Asian people's attendance on and understanding of the course, were also identified in the second major theme, *Facilitators*, which will be discussed now. Participants' experiences of delivering EPP to South Asian groups had allowed them to identify features that, if present, they believed would facilitate the course, both from their own perspectives as tutors, and in how they perceived that attendees would receive it.

One participant described the difficulties that she had encountered when delivering EPP to attendees from different religious and linguistic backgrounds, which she believed negatively impacted upon their engagement. This led her to advocate that courses require tailoring around religious beliefs and that attendees should be recruited by religion *and* language; this appears to have been successful for another participant. Feeling a useful member of society has previously been reported as a motivational factor among SMP tutors (Barlow and Hainsworth, 2001), so it appears plausible that the highly culturally diverse Course failed to provide the tutor with this sense, in a way that the Punjabi-specific course did. Clearly, such tailoring (which could, perhaps, address the issues around course materials, raised earlier) would need to be

undertaken in partnership with the relevant communities, to ensure its fitness for purpose, as previously discussed. There is some precedent for this in the literature, with Griffiths et al.'s (2005) RCT of Bangladeshis, who were recruited onto a course that had been specifically adapted to reflect the local dialect that attendees spoke, and Islamic culture. Thus, this finding confirms some Study I participants' perceptions that language and religion may be areas that EPP could be tailored for South Asian attendees. Similarly it confirms an overarching observation from the first study that EPP delivery in a multi-cultural society is highly complex.

Similarly, participants' delivery experiences provided insight into access facilitators that could help South Asians attend the EPP. For example, one participant suggested an EPP presence in South Asian communities' religious institutions, in order to raise its profile, and recruit in these places. The use of faith-based and faith-placed health education interventions that aim to help address health disparities in underserved communities, are widespread in the USA (e.g. breast cancer education amongst Black African Americans, Rodriguez et al., 2009). This may be because such interventions are perceived as socially, culturally, and spiritually acceptable to members (Wilcox et al., 2006), confirming this study participant's view. In their 2004 review, DeHaven et al. (2004) concluded that faith-based and faith-placed programmes produced positive outcomes, including increased disease knowledge, improved screening behaviours and reduced disease symptoms. Yet there appears to be little in the literature to suggest that this strategy is recognised in the UK, so identifying an area ripe for exploration. Similarly, the use of Indian TV channels that are available in the UK presents a number of novel possibilities. Whilst television has been used as a medium for health behaviour change (e.g. McVey and Stapleton, 2000), it does not appear to have been considered either for self-management education, or specifically for South Asian communities in the UK. Perhaps this medium could be used for EPP-CiC to advertise tailored Courses. Hypothetically, South Asian tutors and previous EPP attendees could appear on talk shows to promote the experiential benefits that they derived from attendance, or perhaps a documentary could be

commissioned – like the yoga scientists. However, television would lack the level of interactivity and the group-based learning approach on which the self-efficacy element of EPP is based, probably rendering it unsuitable to actually broadcast tailored EPP courses. Thus, this unexpected finding suggests an exciting direction for future research.

A noteworthy observation of the current study in this stark contrast it provides in comparison with the previous study, whose experiences of delivery had largely been unproblematic. This may be attributable to the likelihood that English-speaking South Asian EPP attendees that the White tutors had encountered were acculturated, and therefore better understood the course. This Study unequivocally confirms the need for involvement of the target community when developing any targeted intervention.

### **5.5.2 Limitations**

A number of caveats in Study II need to be addressed. The low EPP attendance rates amongst people from South Asian backgrounds at the time of the interviews, meant that the South Asian tutors interviewed here had only limited experience of delivering to South Asian attendees. Clearly, this will have influenced participants' experiences and views expressed. The breadth of results presented in this Chapter, however, indicates that this does not appear to have unduly restricted Study II's findings. Another potential limitation is that of socially desirable answering, particularly as my ethnicity differed from participants', and the sensitive nature of the topic. It is possible that participants may have given 'politically correct' responses, perhaps either for fear of judgement, or of offending me. However, participants' right to anonymity was stressed prior to, and throughout the interviews as necessary, to assure participants that they could speak freely. Given the diversity of answers, and participants' open criticism of some aspects of the EPP, response bias does not appear to have compromised the current study. Another consideration is that many of the tentative recommendations suggested herein, that arose from

participants' interviews, may be difficult to operationalise, given budgetary constraints and timescales for EPP's implementation. Should any of the suggestions be employed, then efficacy/effectiveness studies would be required. Thus, Study II may represent an academic exercise in ideology.

### 5.5.3 Strengths

Study II also has a number of strengths. It captured a snapshot of an early phase in the national implementation of EPP, highlighting a number of cultural 'teething problems' that have subsequently been resolved. Thus, the results may provide informative strategies for those developing and implementing similar health interventions to South Asian groups. Similarly, one participant's depiction of Sikh culture in transition may represent a useful reference point for the future. The highly detailed descriptions have provided thought-provoking insights into these Punjabi Sikh participants' experiences of delivering courses to South Asian attendees, afforded by the study's qualitative design. Whilst not intended to be generalisable, this study may, however, represent a useful starting point for future research in this area. Studies I and II can be considered 'multi-perspectival' (Clare, 2002 in Smith, 2009) as they explore the phenomenon of delivering EPP to South Asian attendees, from the perspectives of both White and South Asian tutors. This is considered a 'bolder design' by Smith (pg.52, 2009) for the additional dimension that is brought to the phenomenon under investigation.

### 5.6 Chapter Five Summary

This small-scale, in-depth, study identified the need to recruit attendees, and deliver both taster sessions and courses in faith-placed locations, in order to raise awareness about EPP, and overcome misperceptions about its purpose and elements of its content. Study II further revealed that the availability of highly refined, single-sex courses, comprising attendees who speak the same language, are from the same religion and caste may help with South Asian

recruitment, engagement and delivery. The need for non-text-dependent innovations in course materials and delivery media, incorporating culturally-specific self-management guidance, developed in partnership with community-members who have low literacy and health literacy, would address the substantial barriers that were recognised by participants.

It was evident from this Study's findings that South Asian community-members may have very different experiences of living with a LTHC than has been previously understood in mainstream research. Exploring these experiences may reveal potential barriers to facilitators to their EPP attendance and performance of self-management behaviours.

# Chapter Six: Study IIIa

**"First I take a tablet. Rest... I do yoga sitting down"**

*Punjabi Sikh women, pre-EPP*

## Chapter Contents

### 6.1 Study IIIa objectives

### 6.2 Recruitment and Participants

### 6.3 Data-collection, translation and Analysis

### 6.4 Findings

### 6.5 Discussion

### 6.6 Chapter Six Summary

#### 6.1 Study IIIa objectives

The previous Chapter revealed insight into seldom-considered aspects of EPP's cultural competence. Participants demonstrated that features of the EPP's recruitment strategy, delivery mode, course materials and content represented potential barriers and facilitators for South Asian people to attend and engage with EPP and perform self-management behaviours. It was evident from the tutors' accounts of delivering EPP to Punjabi Sikh attendees that Punjabi Sikh community-members would provide further insight into their experiences of living with and self-managing a LTHC, and their perceptions of EPP. The objectives of Study IIIa, were therefore, to:

1. **Describe Punjabi Sikh women's experiences of living with osteoarthritis or rheumatoid arthritis; and**

## **2. Identify perceived barriers and facilitators to Punjabi Sikh women's self-management practices, including attendance on a self-management programme.**

The interviews to achieve these objectives took place prior to participants' attendance on EPP. The follow-up Study, examining participants' experiences of attending EPP and subsequent self-management experiences, is reported in the next Chapter.

### **6.2 Participants and Recruitment**

#### **6.2.1 Participants**

The necessity for homogeneity of participants' experiences that the present study's aims and methodology demanded, required decisions to be made about which South Asian subgroup and LTHC would be studied; these are considered now.

The purposive, pragmatic sampling technique that had been necessarily adopted in the previous study had coincidentally produced a sample of female Punjabi Sikh Indian participants. Using data from the General Household Survey (1991–96) to investigate differences in health status amongst ME elders in Britain, Evandrou (2000) found that Indian women aged >60 years were 2.5 times more likely to report limiting long-standing illness, and 2.71 times more likely, to report 'not good' health, than their White counterparts. Half of Indian elders were in the poorest 20 per cent of the income distribution, compared with a fifth of White elders. By recruiting Sikh participants, detailed exploration of the influence of any specific religious and spiritual beliefs on their health experiences, self-management practices, etc. would be possible (e.g. Griffiths et al., 2005; Ismail et al., 2005; Labun and Emblen, 2007). In the interests of homogeneity (a prerequisite to IPA research) across the three studies involving South Asian participants in the current thesis, Punjabi Sikh Indian women were therefore purposively sampled for Study IIIa interviews.



Musculoskeletal diseases (MSDs), including arthritis, are common, their effect is pervasive and they cause severe long-term pain, physical disability and significantly affect psychosocial status (Woolf, 2007). European arthritis prevalence data show that 20–30 per cent of adults are affected by musculoskeletal pain at any given time within the European Union. MSDs are the second most common reason for consulting a doctor, and constitute 10–20 per cent of the primary care practice in most European countries, highlighting the financial burden (Woolf, 2007). In the UK, 914,200 (37.3%) of a total of 2,468,900 UK, Disability Living Allowance claims were for arthritis, muscle, bone and joint disease and back ailments in 2003. This represents more claims than for mental health conditions, learning difficulties, heart disease, stroke and malignant disease combined (ONS, 2003).

The effects of MSDs amongst South Asian populations are considerable. A large-scale survey of South Asian and White people in Manchester and Birmingham, found that significantly more South Asians reported widespread pain (MacFarlane et al., 2005); regrettably, detailed analysis by South Asian subgroup is not provided. Similarly, Allison et al. (2002) found that musculoskeletal symptoms were more common among people from BME groups than in the White population in the Northwest of England, and pain in multiple sites was more prevalent among some South Asian people (Allison et al., 2002). Specifically, 21% of White women aged 45–64 reported widespread pain, compared with 52% of Indian women (Allison et al., 2002). In their UK survey, Palmer et al. (2007) reported the prevalence of widespread pain in Punjabi Indians was 22%, compared with nine per cent in European participants. The authors of these reports argued that the social, cultural, and psychological differences that may underlie the varying pain profiles, and the health needs that follow, warrant further investigation. However, as the following paragraphs highlight, little evidence exists about South Asian people's MSD experiences.

Osteoarthritis (OA) is the most common form of arthritis in the world and is a leading cause of disability in the elderly (Issa and Sharma, 2006; Arden and Nevitt, 2005). Recognised as one of the top ten causes of disability in Europe, and, globally, OA is the fourth most frequent predicted cause of health problems in females and the eighth in males (Woolf, 2007). After the age of 50 the prevalence and incidence of 'generalized OA' in the hand, knee and in multiple joints, increase sharply and is significantly greater in women than in men (Arden and Nevitt, 2005); oestrogen deficiency is one possible cause. Worldwide prevalence estimates suggest OA affects 9.6% of men and 18% of women aged >60 years (Organ, 2003; Woolf, 2007). Whilst Arden and Nevitt's (2005) review considered OA prevalence differences between Black, White and Chinese populations, no UK OA prevalence data by ethnicity were located. However, in a Canadian cohort, women with OA experienced higher level of depressed mood, greater pain and fatigue, and more stressful life events (Sale *et al.*, 2008) than males. This suggests that in addition to greater prevalence of OA, females may experience this disease more negatively than males. Yet there is a dearth of literature examining OA among people from South Asian backgrounds, with little known about these groups' experiences.

Rheumatoid arthritis (RA) affects 0.3–1.0% of the general population, is again more prevalent among women (Organ, 2003; Woolf, 2007). However, data were based on 'Caucasian Europeans' obtained from extrapolations from Europe and North America, with no mention of BME prevalence in the report. Similarly, in UK RA prevalence estimates, Symmonds, Turner, Webb *et al.* (2002) found the minimum likely prevalence to be 0.44% amongst men and 1.16% amongst women; however, prevalence data by ethnicity are again not reported. The increased prevalence of both OA and RA amongst women confirmed the decision to seek female participants. In another UK study, Griffiths *et al.* (2000) compared North Indian (including those from Punjabi backgrounds) or Pakistani RA patients with northern Europeans, across a number of measures including immunogenetic analysis, blood tests, X-rays and questionnaires. Immunogenetic differences were revealed; Asians had

significantly fewer bony erosions and rarely had nodules, but had similar levels of rheumatoid factor positivity, number of swollen joints and inflammation levels as the Europeans. Yet Asian patients reported more tender joints and had significantly lower Health Assessment Questionnaire scores than Europeans, confirming greater RA pain prevalence amongst South Asians (Griffiths et al., 2000). As with OA, there is a dearth of literature examining South Asian people's RA experiences, which demands attention.

Both OA and RA lead to pain and joint mobility difficulties caused by inflammation (although the causes of inflammation vary), are incurable and require careful management to minimise progression. For example, **arc** recommend combinations of joint care, drug treatment and balancing exercise with rest ([www.arc.org.uk](http://www.arc.org.uk)). Thus, whilst the causes of the two diseases differ, similarities exist between patients' experiences; the inclusion of both was likely to increase the number of participants to ensure a sufficient sample size without compromising homogeneity of experience.

Osteomalacia (rickets) was also considered as an inclusion criterion in the present study, but was ruled out, for the following reasons. Caused by vitamin D deficiency, osteomalacia leads to generalised bone pain and muscle weakness; unlike OA and RA, joint mobility is unaffected. In most cases, after several months of treatment with vitamin D supplements, the osteomalacia is cured and symptoms disappear ([www.arc.org.uk](http://www.arc.org.uk)). In the UK, it is most prevalent amongst South Asian women who wear traditional dress such as the burka (arc, 2002). It was understood, following discussions with the local South Asian healthcare specialists and Sikh acquaintances, that the Punjabi Sikh women in Coventry do not wear burkas, which are Muslim attire. Given the necessity of homogeneity amongst participants and experiences in IPA research (Smith, 2003), the inclusion of Muslim women with osteomalacia, in addition to Punjabi Sikh women with OA/RA, was not considered methodologically appropriate. Indeed, further diversification of both the

participant and disease groups may have served to detract from the design of this study.

Purposive sampling therefore targeted Punjabi Sikh Indian women with OA or RA.

### **6.2.2 Recruitment**

Recruitment used a "time-venue-based" technique (Crosby et al., 2009), in which participants were approached in their usual meeting-place. The BME EPP Lead, JS, a Punjabi-speaker, facilitated my access to a group of Punjabi Sikh women who meet weekly for a social event, at a community centre adjoining a Gurdwara (Sikh temple), which is situated in an area of multiple deprivation in Coventry (ONS, 2003). JS had translated the Information Pack (see Appendix 3), containing the Information Sheet, Informed Consent, Demographic data-collection and interview schedule, into Punjabi. We attended together, and JS read the Information Sheet aloud, in Punjabi, for the benefit of any potential participant who could not read. JS explained the inclusion/exclusion criteria to the group, in Punjabi, and asked for potential participants for interviews to be conducted over the subsequent weeks; ten women who fulfilled the inclusion criteria were identified. Such purposive sampling is recognised as potentially useful among ME groups (Crosby et al., 2009) and is usual in IPA studies (Smith et al., 2009). Potential participants were left with Information Packs, in Punjabi or English at their discretion, so that they had a 'cooling off' period, should they decide that they no longer wished to participate. However, no-one who agreed to be interviewed subsequently withdrew. Coventry University Ethical Committee approval was obtained before commencement of the study (please see Appendix Two). No distress was likely to occur to participants as a result of taking part in this Study.

### ***Participants' Demographics***

The 10 Punjabi Sikh female participants were aged 55-73 years (mean 65.2

years), and all were first generation immigrants from India. One participant had RA, eight had OA, and one had both; nine participants had comorbidities including cardiovascular disease, hypertension, osteoporosis, diabetes and endometriosis. Every participant gave the language that she spoke the most as Punjabi, with other languages spoken including English, Hindi and Gujarati. All are Sikh.

**Sample size** The necessity for small, homogenous sample size has been examined earlier in this thesis. Sufficient breadth of experience and richness of data were expected to arise from interviews with 10 English- or Punjabi-speakers to permit detailed analysis. Larger numbers of participants were recruited in this study than in the previous two, to allow for attrition during the follow-up Study.

### 6.3 Data collection, Translation and Analysis

Informed consent was obtained for every participant, in the language of their choice, prior to the commencement of each interview, which was also conducted in the language of participants' choice. Chapter 3.2 discussed the complexities of research involving interpreters and translators. All interviews were digitally recorded, with participants' consent.

#### 6.3.1 Data-collection

##### Punjabi-language data-collection

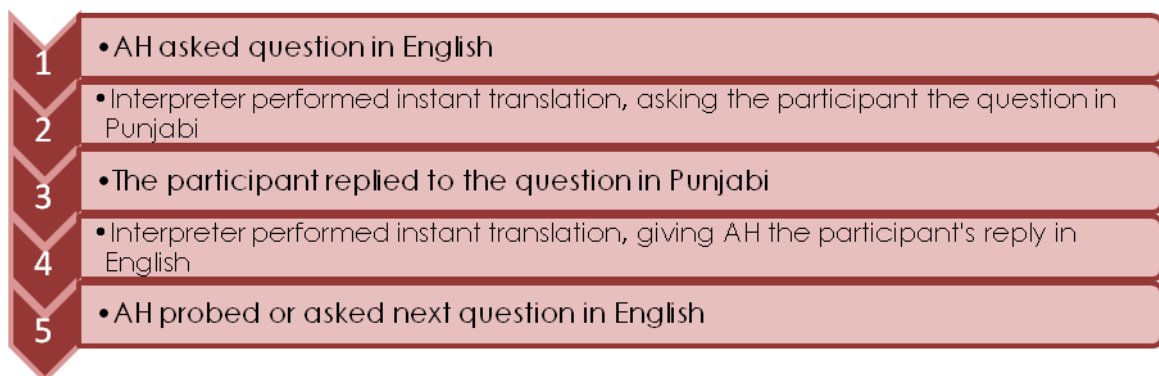
I provided JS with a copy of the semi-structured interview schedule in advance, which was informed by the previous Studies' findings and the research aims (see Appendix 3). JS confirmed the questions were likely to be understandable to participants, and should elicit the type of detailed experiential responses that I sought. I was present throughout every interview for any clarification that may be necessary, whilst JS conducted interviews with six participants in Punjabi.

## English-language data-collection

I conducted interviews with four participants in English. JS was present throughout every interview for any clarification that may be necessary.

## Punjabi and English-language data-collection

One participant commenced her interview with me in English, but it became apparent that we were unable to entirely understand each other. JS was invited to step in and a three-way interview was performed. The procedure is represented diagrammatically, in Figure 6.1:



**Figure 6.1: Three-way interview process**

This three-way interview process allowed the participant to convey her experiences to me effectively.

### 6.3.2 Translation and Transcription Procedures

#### Punjabi interview data

JS hand wrote the six verbatim transcripts in Punjabi. Using her hand-written Punjabi transcripts, JS then translated and transcribed the interviews into English. JS met the validator, a professional NHS interpreter, with the audio files and both the Punjabi and English transcripts, in order to verify the accuracy of the translations. Where queries around JS's choice of English words occurred, the audio was listened to by both, and differences resolved. For example, one

participant used the Punjabi expression 'satsang' that the interpreter translated into 'Ladies Day'. However, the validator did not feel that this adequately conveyed the celebratory nature of the event, which has a strong religious component, so this was returned to the original Punjabi and I was provided with a verbal explanation.

**English interview data**

The data from the four English-language interviews were transcribed verbatim, and line-numbered, as in the previous Studies.

**Punjabi and English interview data**

As detailed above for the Punjabi sections of the interview. English sections were transcribed verbatim, and line-numbered prior to analysis.

**6.3.3 Analysis**

Analysis of the English transcripts used the IPA approach (Smith et al., 1999; Osborne and Smith, 2003), previously described in Chapter 4.3. My analysis therefore followed the same descriptive and interpretative procedure as in the previous Studies. In the transcript extracts presented in the Findings of this Study, all participants have been given pseudonyms.

**6.4 Findings**

**Table 6.1: Major themes and Subthemes arising from Study IIIa analysis**

Major themes	Subthemes
<i>Constraints vs. abundance</i>	<i>Constraints of arthritis</i>
	<i>The abundant self-management palette</i>
<i>Managing the tensions</i>	<i>Perceived incompatibilities</i>
	<i>Motivated for engagement</i>

As Table 6.1 shows, two major themes comprising five sub-themes were identified from the analysis. These are my interpretations of the data; I accept that others may exist. These Findings will now be discussed in turn.

#### 6.4.1 Punjabi Sikh experiences of living with arthritis

**Table 6.2. 1<sup>st</sup> Major Theme and Subthemes arising from Study IIIa analysis**

Major themes	Subthemes
<b><i>Constraints vs. abundance</i></b>	<i>Constraints of arthritis</i>
	<i>The abundant self-management palette</i>

The first major theme collates numerous illuminating examples of participants' psychological, physical, practical and spiritual experiences of living with and self-managing OA or RA. Participants' desire to improve their lives with arthritis is discernable throughout.

#### Constraints of arthritis

The first subtheme encapsulates participants' arthritis experiences at a number of different, overlapping, levels. I start by highlighting participants' retrospective and ongoing emotional states, arising from their arthritis experiences. Next, I address aspects of participants' psychological and physical experiences, considering the issues of pain and fatigue.

#### **Psychological constraints of arthritis**

The first quotation highlights the devastating psychological impact that the diagnosis of arthritis had on one participant:

**AH: *What's it like for you, in your day-to-day life, living with arthritis?***

**Nirmal: *Well, you get used to it. In the beginning, you feel inside yourself, broken, no life.***



This quote powerfully conveys the sense that Nirmal had felt that her life was ruined and effectively over. Although I asked about her daily life with arthritis, Nirmal responded about her experience of diagnosis, suggesting the continued significance of this event to her. It is clear that Nirmal understood the potentially life-changing implications that the diagnosis carried. However, Nirmal's words also indicated that she had now overcome the initial distress of diagnosis, which represented a transient stage of psychological adjustment to her arthritis.

Another participant described the ongoing impact of her arthritis as epitomized by her apparent physical frailty and poor balance. However, the psychological consequence of these symptoms, was fear:

***Harnam: It is like this ... It is very disturbing... [Silence] I need support; I cannot go anywhere on my own. Your uncle drops me outside in the car... how to keep my balance right... I do walk. My knees shake and I fall down... I want my legs' arthritis to get better... I am frightened in case I fall down. This is my problem... That is why I do not leave home and prefer to stay home in case I fall down.... I prefer to stay home.***

It is apparent that Harnam experienced considerable distress as a result of her arthritis, which had seriously undermined her autonomy, and, interpretatively, her self-efficacy. It is unclear what type of 'support' Harnam was referring to – physical, such as a stick or frame, or pragmatic, such as the help that she described; evidently Harnam understood that she could not manage alone. Whilst now dependent upon transport, Harnam's current lift arrangements did, however, allow her to overcome her fear sufficiently to attend the social group. Thus Harnam's anxiety about falling was the most debilitating feature of her experience, causing her to remain in the perceived safety of her home.

### **Psychological and Physical constraints of arthritis**

**Pain**, stiffness and swelling were physical symptoms of living with arthritis that were widely reported by participants, and which had serious physical and psychological consequences. The following quotation provides a particularly

vivid insight into the severity of the pain that Nirmal experienced, and the rapid detrimental effect of this, and her stiffness, to her home life:

***Nirmal: It's that whole, that pain, I can't explain, that pain is like somebody hitting you with hammer – it's that pain in my hands! ...It started in the hands, then up to the arms, and in 2 months – crippled!! Within 2 months I wasn't, I couldn't move. Even in the kitchen if somebody came, then I couldn't get anything.***

The metaphor of arthritis pain as comparable to that from a hammer blow, powerfully conveys the overwhelming nature of this pain. Exacerbated by the swiftness of the disease onset, Nirmal was soon unable to offer hospitality for visitors, as she lost normal role-function. Thus, Nirmal understood that the arthritis appeared to cause her not only physical impairment, but also social impairment, as the excruciating pain and stiffness left her unable to provide for guests.

In addition to the severity of pain, many participants highlighted the widespread nature of the arthritis pain, as Ravinder described:

***AH: What's it like for you living with arthritis.. how does it affect your daily life?***

***Ravinder: It's very hard to live with the pain. ...Yes I have lots in my back, my hands, the feet, all over my wrists – it's very bad.***

Asked a general question about her arthritis, Ravinder responded about her pain, suggesting her experience was dominated by this. Ravinder's perception of having extensive pain appeared to equate to her understanding about her disease severity. This could have served to disempower her psychologically, in addition to the physical symptoms she experienced.

**Fatigue** The principal symptom that another participant experienced from her arthritis, was excessive fatigue. Satanam described her morning lethargy, despite her motivation to start the day's routines:

***Satanam: I do not wake up... I feel very sleepy. Sleep ... my eyes are stuck like glue; I feel so sleepy... I cannot open my eyes.***

**J: Ok. Is this the effect of the medicine?**

**Satanam: No, no... I sleep too much ... I cannot get up in the morning. I want to get up, I want to do yoga, come to the Gurdwara, do exercise... My body just does not work... I get up 8-9 o'clock, slowly, slowly, then I drink tea.**

**J: What is the reason for this?**

**Satanam: Reason, I do not know why I feel so sleepy.**

Satanam's physical state was in sharp contrast to her psychological motivation to undertake her physical and spiritual activities. "My body just does not work" suggests a sense of frustration that her fatigue imposed upon her daily routines. Whilst unable to identify the cause of her fatigue, Satanam did not, however, attribute it to a side-effect of her medication, for example, or a comorbid LTHC.

### **Summary**

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Within the first major theme of Constraints versus abundance, this subtheme Constraints of arthritis has highlighted the Punjabi Sikh women's psychological and physical arthritis experiences. These included the psychological adjustment need following diagnosis, fear, and pain and fatigue.

#### **6.4.2 The abundant self-management palette**

The Punjabi Sikh women demonstrated that they were highly adept at selecting appropriate behaviours from a plentiful and varied supply of resources. Every participant had adapted some area of life in order to better deal with her arthritis, often involving culturally-appropriate and individually tailored self-management practices. The following aims to capture an overview of these numerous behaviours.

**Prescription medication** Participants were all being prescribed painkillers for their arthritis. In the following extract, Ravinder described the beneficial effects that her prescription medication had on her daily life activities:

**AH: Is there anything you can do that makes that [pain] better?**

**Ravinder: Take two tablets! [Both laugh]**

**AH: Painkillers?**

**Ravinder: Painkillers, yes.**

**AH: Is that something you got from the doctor or is it something you buy?**

**Ravinder: From doctor. He gave me that... The pain is gone and I can work, my housework and I can come here on Mondays to see my friends. So I pass my time. So I carry on. If I don't take my tablets, right arm, all the time [unclear - I can't cook?]**

Ravinder understood that taking the prescription medication allowed her to fulfil her domestic and social roles when not in pain, although the ironic laughter infers that she might have considered analgesic dependence to be undesirable. However, when considering her arthritis experience on days that she did not take her tablets, the pain in her arm evidently inhibited her lifestyle. Ravinder made a clear, direct causal attribution between the presence or absence of pain in relation to her medication, which she understood allowed her to manage her pain effectively.

However, other participants were less positive about the potential benefits of medication. For example, in the first quote, below, Varinder indicated that her tablets were entirely ineffective, but in the second quote, taken from later in the same interview, she suggested that medicine had a suppressive effect on her pain:

**J: What other ways do you use to manage your arthritis, so that it gets better?**

**Varinder: Firstly, taking tablets, I took tablets for a long time. It did not make any difference.**

\* \* \*

**Varinder: With medicine, the pain ... is suppressed... It is like this. The pain is still there, but it is suppressed. I cannot walk. I can hardly walk... I go to the bathroom ... I can hardly walk. I cannot put weight on my feet... My feet, I am about to fall down. I could hardly walk, in case I fall down.**

Varinder evidently felt that her extended medication regime should have reduced the pain that she was experiencing, which suggests that she associated long-term usage with positive outcomes. However, her negative perception about the effectiveness of her tablets was modified slightly in the second quote, which indicated that the tablets did have limited benefit. It is evident that her normal daily functioning was nonetheless severely restricted by the pain that weight-bearing caused, even within her own home, with medication providing only limited relief. Varinder's understanding of painkillers was that they should eliminate the pain, which was dissonant with what she experienced in reality, thus giving rise to her ambivalent view about prescribed medicines.

Another participant conceded that tablets were effective for pain-relief, but described her fundamental dislike of taking medication, owing to their perceived side-effects:

**Ravinder: ... if I take two tablets every day, I can carry on!! If I don't take [tablets], sometimes I fed up with and didn't take, then it's a bit sore, oh I can't cope with, I have to take! ... Because last Thursday I went to the doctor again, I told him 'Every day I have to take two tablets, my mind goes sick' because sometimes alright to take pain tablet, but not every day, two! And gave me another tablet ... 'Then your muscle is relaxed and you'll be all right.' .. It is too strong and I didn't take any more!**

**AH: So will you go back to your doctor –**

**Ravinder: I'll try, but some tablets when I eat, take, I feel sick. So I don't want that. And once he said 'You take this', but I got constipation?! So he said 'You take this tablet with that one' but I don't want that!! I don't want all that – too many!! [both laugh]**

Ravinder's experience of taking tablets acknowledged that their analgesic effect allowed her to live her life. However, she became disheartened with this apparent reliance on tablets, worried both about the psychological impact of medication and its side-effects, so periodically discontinued their use. This suggests that Ravinder had a negative medication perception, which, in turn, adversely affected her compliance/concordance. Of interest, is Ravinder's perception that two tablets per day was excessive, suggesting that one tablet

with a higher dose might address her concern. However, Ravinder understood that the alternative medication that her GP prescribed, apparently in response to this, was 'too strong', causing unpleasant side-effects. The prescription of further medication to combat these, served to unintentionally negate the purpose of Ravinder's initial request, as it did not address her underlying concern about the quantity of tablets that she was consuming.

Many participants made dietary modifications and took herbal remedies in order to manage their LTHC; these are summarised alphabetically, in Box 6.1. This table is included as space restrictions in this thesis preclude individual reports and detailed analysis of each. This gives some idea of the extensive nature of this self-management practice, amongst Study IIIa participants.

Aloe vera	Fennel	Neem
Aniseed	Fried food *	Pineapple*
Cardamom	Garlic	Rice*
Chutney*	Ghee	Sesame seed oil
Cinnamon	Ginger	'Sharp' foods*
Citrus*	Karela	Yogurt*
Cloves	Linden ice	

\* Adverse effect

**Box 6.1: Culinary and herbal remedies used**

The number of participants reporting use of individual substances is provided in parentheses for information. Some examples are now provided.

**Dietary modification** Mandeep found her condition to be unpredictable, attributing fluctuations in the symptoms that she experienced to her food consumption, having read that citrus fruits aggravate arthritis:

**AH: Can you tell me what seems to help or make it worse?**

**Mandeep: Well I found out it's the food! I checked the booklet by Margaret Hill<sup>6</sup> about arthritis and you know, drugs? ... So she says it's the food and I tried that on myself – especially the citrus fruit, she said cut it out. And I found in me, if I drink orange juice it goes straight to knees... That's what I was reading about. Whenever I eat citrus fruit, eat or drink, I have pain it goes straight to my knees. So I can tell that it is true that food affects me.**

Mandeep's personal experience confirmed her understanding that dietary intake influenced her disease status, especially that citrus fruit consumption caused her knee pain. It is unclear whether Mandeep held this health belief prior to reading about it. Self-motivated to seek health information, and to effect behaviour change, Mandeep appears to be an active self-manager.

Another participant also made dietary modifications in order to manage her musculoskeletal disease, but rather than eliminating certain produce, Harnam included particular foods that she considered to be beneficial:

**J: What other things have you tried that help?**

**Harnam: In terms of eating, it is vegetables etc. Mostly karela. Sometimes I make curry with Aloe vera. Aloe vera is good for arthritis. Take purified ghee, trim Aloe vera and add aniseed to it. First wash it, then trim it, cut it into pieces with the skin on, add aniseed to it. Do not burn it. Do the same with karela.**

**J: Does it help you?**

**Harnam: It gives me comfort that I will get better... It helps a little then.**

Harnam's belief system attributed success to natural substances, particularly the medicinal benefits of aloe vera, for improving arthritis, although she did not indicate how or why improvement occurred. This quote suggests that, like the previous participant, pro-active self-management is inherently acceptable to Harnam. Her final comment of the extract is interesting: it suggests that the participant understood that the vegetable curry that she described is a comfort food, which is of some perceived benefit. Interpretatively, her food

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<sup>6</sup> Hills, M. Treating Arthritis: The Drug Free Way **Paperback:** 128 pages **Publisher:** Sheldon Press (18 Aug 2006) **Language** English **ISBN-10:** 1847090052 **ISBN-13:** 978-1847090058

preparation activities may, therefore, serve to improve Harnam's health self-efficacy, as she understood that she was helping herself.

**Traditional herbal remedies** Many participants used traditional Indian herbal remedies to self-manage their arthritis. For example, Varinder's mother had given her neem tea for the first time the previous day, in order to help with the participant's pain:

***Varinder: Yesterday, I ... drank ... there is a tea that is neem ... It is very bitter, it is given to me, it is dried ... she said, take a spoon, drink it, eat it ... drink water of that ... I said that I am not taking it like that. Maybe it will make my illness better?.... I boiled it yesterday; and drank it for the first time. I will see it today again when I go back... I do not know why this hurts so much. ... It [neem] comes from India... Now I will drink this; I will boil it. All the effect will be in the water; I will try it. My mother has made small packs ...[ laughs]. I was unable to walk.***

Varinder appeared to overcome some initial reticence about consuming the dried neem, seeming willing to tolerate the tea's unpalatable taste, and hopeful that it may reduce her severe pain. The participant understood that the preparation would not confer instant benefits, which suggests that she may believe the neem tea to have a cumulative effect (despite having taken prescription medication for long periods, as previously reported). However, Varinder seemed to appreciate this opportunity to manage her pain, apparently understanding that the therapeutic properties of the Indian neem were contained in the infusion that she was going to drink. The irony, or perhaps embarrassment, of the participant's (presumably quite elderly) mother treating her, is explained by Varinder's final statement: the previous day's arthritis pain had left her incapable of walking. This state of debilitation may have further motivated Varinder to try the traditional remedy. The quote also offers insight into the inter-generation transmission of traditional knowledge.

Another participant used a herbal remedy that had been suggested by a friend, in a topical application that was massaged into her arthritic joint:



**Mandeep:** For example, recently one of my friends recommended me sesame seed oil? And erm, you have to put two spices in it: cloves and garlic. And you have to boil it and boil it, boil it. For half an hour! Then cool it and put it in bottle and put little bit on it [knee].

**AH:** You actually apply that to your knee?

**Mandeep:** Yes, and rub it in, rub it in, like a little massage. And massage is good for it. That's what all the ladies are recommending as well, massage is good for you. So you find these little things, which are [unclear] for your body. Again I haven't found any miracle yet, which can tell!

This again confirmed participants' willingness to actively engage in experimental self-management behaviours that may have a beneficial effect on their arthritis. The hearsay recommendation of this herbal remedy, combined with the peer-reported effectiveness of massage in arthritis, evidently contributed to Mandeep's enterprise, confirming the importance of experiential evidence to her. As previously noted, the act of self-care itself may have served to enhance participants' self-efficacy, and therefore represent a positive psychological self-management behaviour. Mandeep's final comments suggest that the temporary hope offered by such remedies, served to motivate her ongoing quest for a miracle cure.

Another participant confirmed that she used dietary modification, avoiding substances she considers to be detrimental to her condition, **and** traditional herbal remedies that she believed to be beneficial, plus her prescription medication, in combination, tailored to suit her personal needs:

**Ravinder:** I have to take some Indian things to help me, like ginger, a few things help our plight. A few things feel suitable for me and I take!

**AH:** So ginger helps does it?!

**Ravinder:** Ginger helps, yes you put ginger with, I don't know how to describe. Ginger is very good for arthritis. And some few things more. Because we Indian people think, garlic, is very good... But I can't take much because I've got problem, erm, toilet things, so ... I don't take it every day. We don't depend on our doctor all the time, we have to depend on ourselves sometimes! So we eat what is good for us, not what is bad for us. So like chutney? Erm, I suppose something like this, sharp things, I I can't eat.

**AH: Does chutney make your arthritis worse?**

**Ravinder: It makes it worse, yes. And er fried things, it gets worse... It's very bad for the arthritis...**

**AH: So would you rather manage it with the ginger and the garlic, than taking the tablets, or a bit of both?**

**Ravinder: No I have to take the tablets! I've tried to do without as well. If I, I'm all right with that pain, that I don't want the tablets, I don't want them, I can't take this, they're too much!**

The first line of this quotation shows that Ravinder considered the self-management techniques that she described, to be culturally situated, although clearly, many of the substances she mentioned are not uniquely Indian. Deliberately tailored to meet her personal needs, and thus avoiding unpleasant side-effects, this participant sought active involvement in the self-management of her arthritis. Ravinder's perception that both 'sharp' and fatty foods are detrimental to arthritis may reflect a culturally-specific belief system around the medicinal properties of food; illness perceptions are discussed in the next section. However, her best efforts at self-management using Ayurvedic techniques were necessarily supplemented by painkillers, despite her palpable aversion to them.

**Yoga** Several participants were aware that exercise was beneficial to their joint pain and stiffness, and had found that tailored yoga eased these symptoms. For example, the following quote highlights how one participant was selective in her choice of the particular yoga exercises that she found to be compatible with her restricted mobility:

**J: What is it like to live with the pain of arthritis?**

**Varinder: I feel very tired, I cannot do any work ... my knees hurt ... I cannot lift my leg to walk. Then I do exercise with my legs and I am able to walk a little. I got up in the morning and did a little bit of exercise. They show on telly ... I get up at seven in the morning ... Yesterday, I was unable to walk.**

**J: Which exercise do you do?**

***Varinder: Yoga that's shown on telly. Yes, I did it yesterday and today... I do it at home a little bit now. I do not do hard one ... I do the easy ones. I move my arms here and there. Very slowly.***

Varinder was asked about her arthritis pain, yet responded about fatigue, stiffness, the impact of the disease on her quality of life, in addition to the pain, thus highlighting the far-reaching consequences that the condition has upon this participant's life. She immediately, and without prompting, then raised the issue of exercise, demonstrating that she understood its central importance in managing her arthritis. Indeed, Varinder's yoga exercises, which she specifically selected to meet her personal needs, appeared to make the difference between being able to walk – and not. This finding offers some confirmation of Karamdeep's perception in the previous Study, that Punjabi Sikh people watch yoga programmes on television

The following excerpt shows that in addition to modified yoga, however, another participant still needed to rest, and take her prescription medication:

***J: What ways have you found of making it easier to live with your arthritis?***

***Satanam: First, I take a tablet. Rest ...***

***J: Do you use any other ways, which will help a little?***

***Satanam: I do exercise, I do yoga sitting down; that also helps.***

Again combining painkillers with tailored self-management behaviours (as previously discussed), Satanam had found that performing yoga in a seated position helped her to benefit from this exercise. Thus, this finding may provide preliminary evidence that yoga may be a culturally-appropriate exercise SM behaviour.

### ***Religious practices and spiritual beliefs***

All participants reported that their Sikh religious practices and spiritual beliefs benefitted their daily lives with arthritis in different ways, often encompassing

spiritual and social support, combined with an element of distraction from the illness experience. For example, Varinder's ill-health often precluded her attendance at the Temple, so she adapted her religious practises to suit her needs at home. As the following eloquently shows, Varinder evidently achieved elevated levels of psychological well-being:

**J: How do you feel when you pray?**

**Varinder: I feel nice. I read the religious book, I feel nice. I feel I am in peace internally and contented... Your mind is stable. If I cannot sit sometimes, I have two, three pillows around me; I lie down and then read my religious book... I am not well sometimes; I lie down and read my religious book...**

**J: How does your religious view, how do you think, how does this affect self-management of your health?**

**Varinder: That is the effect, that's it. It's good. My mind is at peace ... When we come here, we talk to others. That's it... If I will sit in the company of our religious people, my 84 births will be purified... It gives me peace of mind.**

This quotation conveys the tremendous sense of inner peace that Varinder achieved through prayer and her religious reading. When her pain meant that she could neither attend Temple, nor sit to read, Varinder successfully modified her environment to ensure that she was still able to undertake her religious reading. This participant's religious practises evidently conferred notable psychological and emotional stability on her, perhaps acting as cognitive distraction from her symptoms. Similarly, when Varinder was able to attend the Gurdwara, talking with her peers and 'religious people' apparently reassured her that the cycle of reincarnation would eventually end, thus also providing psychosocial and spiritual support.

However, whilst another participant evidently obtained the same psychological rewards from her Sikhism as Varinder, in the extract below, Parmjeet described how visiting the Temple improved her day:

**A: Does reciting God's name make you feel better?**

**(J) Parmjeet: I feel happy. All day. I am happy...**

**A: If you could not get to the Temple for some reason, how would it make you feel?**

**(J) Parmjeet: It feels as if I have never been anywhere. Ya. Here [Gurdwara] the day goes nice.**

**A: It's not a nice day, if you can't come to the Gurdwara?**

**(J) Parmjeet: At home, time just does not go by. It drags on.**

Parmjeet understood there to be a direct causal link between her acts of attending the Gurdwara and, like Varinder above, reciting God's name (praying) and lasting feelings of happiness. One explanation for this is that the prayer may have served as a cognitive distraction from her physical and psychological symptoms, which took place in an environment that facilitated contact with her peers, thus affording her an opportunity for social support. Clearly, for this participant, her religion provided a strong, positive psycho-social self-management strategy. This enduring happiness stands in stark contrast to the profound sense of isolation that Parmjeet experienced when she was unable to attend Temple. There are a number of potential explanations for these polarised experiences. For example, Parmjeet would physically be in the house for longer than normal if unable to attend Gurdwara; she may experience an expectation effect – knowing that her day will be longer, makes it seem disproportionately longer, so contributing to her negative experience of days spent entirely at home. Similarly, with less occurring to occupy her time, and impoverished social support compared with that acquired when attending Temple, the combined lack of physical, spiritual and social stimuli may exacerbate Parmjeet's symptoms. Thus, for Parmjeet, daily Temple attendance was pivotal to her well-being, serving complex, inter-related, psychological and social purposes.

Another participant clearly recognised that the act of prayer itself, in addition to attending the Gurdwara, served multi-faceted beneficial roles at a number of different levels, as this quote shows:

**Mandeep: ...by praying, your mind goes somewhere else instead of your pain, and that helps.**

**AH: So actually helps with the pain while you pray then?**

**Mandeep: Yes, yes, so while you're praying, you forget about your knees! [Both laugh] That's how our religion helps us ... it makes you mentally strong, mentally strong, to tolerate anything. Whatever's out there, it doesn't matter – it's not the end of the world. It stops you worrying, sitting and worrying – the more disease we get, the more we pray actually [laughs]!! So that's how the religion helps us! And more than that – it's like social as well. You talk to other ladies in the courtyard and convince yourself you're not the only one.**

**AH: Some reassurance?**

**Mandeep: Yes, reassurance. And talking to them, you're finding out from your friends what they're taking, what they're recommending.**

Mandeep's insightful quote shows that she understood her religious practices offered effective psychological self-management strategies through cognitive distraction from pain and anxiety, actively praying more when her condition deteriorated. Mandeep was resolute in her understanding of the pivotal role that her spiritual beliefs performed to overcome life's challenges, by encouraging mental strength and tolerance. Similarly, Mandeep acknowledged the psychosocial benefits of interacting with her peer-group, which alleviated feelings of anxiety and social isolation, whilst providing pragmatic support in terms of arthritis treatments. Equally the benefits of cognitive and social distraction from her symptoms when she attends the Gurdwara, are recognised by this participant. Thus, Mandeep understood that her religious practices and spiritual beliefs were fundamental to the physical, psychological, social and spiritual self-management of her arthritis.

Moving from the positive effects that participants' religious practices had on their arthritis, to their spiritual beliefs about health self-management and illness perceptions, it is clear that whilst fatalistic, this did not serve to disempower them. For instance, the following excerpt provides fascinating insight into Satanam's perception as to how her self-management efforts juxtapose with God:

**J: Is it up to you to manage your condition or you have left it up to God about managing your health? What is up to you and what is up to God?**

**Satanam:** *I have left everything to God. God will do everything that God needs to do. [Laughs] Nothing is going to happen with my doing. We want too many things. It is all up to God. I try everything that I can do, but it is all up to God in the end.*

**J:** *Do you think that if you will try, only then things will happen or everything will even happen without you trying? [Pause] ...*

**Satanam:** *I do not know what to say that I do it ... [Laughs] or we do it. [Pause] ...I try to do things ... I go if I need to go anywhere. It is better if God's blessings are on my head. If we both try, then together it works out.*

It is clear from the start of the quote that Satanam did not consider herself to be instrumental in effecting changes in her health, understanding that it was not her place to want for more than she has, perhaps in terms of better health. The end of this quote implies that Satanam had taken some steps to improve her situation, suggesting that this fatalism was not disempowering in her case. Uncertain as to what extent she was responsible, and to what extent God was responsible for her health, and perhaps in response to the second question, Satanam proposed a collaborative effort between herself and God to succeed. Whilst this may represent a 'safe' or socially desirable answer, it suggests that she understood that her efforts were assisted by divine intervention, empowered within God's boundaries.

Participants' faith also appeared to have a positive effect on their acceptance of their LTHC. Ravinder's profound belief in God, for example, helped her to accept that both health and illness are normal parts of life, and thus not, as far as possible, a source of great concern, as the following shows:

**AH:** *You mentioned earlier that erm, you come here and say your prayers. Does your faith feature in your illness, does it help you cope?*

**Ravinder:** *Oh yes, much, much ... help yes! I believe in God, He is everything. But things, if you got nice things, if you healthy life, you have to have this part as well. Because, two things together. So. [pause] We don't worry that much!! We try to get away with what we can!! [Both laugh] We believe that if you've got a healthy life, then there you've got to have time when you've got bad health. So.*

Ravinder's understanding that her negative experience of arthritis was counterbalanced against times in her life of good health, appeared to allow her to deal effectively with her life now, including illness, by accepting it. Talking in the second and third person may indicate that this participant was voicing a cultural belief, rather than her personal opinion.

Similarly, another participant accepted what happened to her body, without recourse to blame-seeking:

**A: *I am also interested in how being Punjabi affects your illness?***

**(J) Parmjeet: *We just recite God's name. There is no God's fault. It's the body. Whatever happens, it's happening inside our body. Ya!***

Parmjeet's biomedical, not spiritual, causal illness attribution and the absence of a search for meaning are noteworthy. Parmjeet accepted her arthritis without blame, suggesting that this participant's faith allowed her to accept her illness.

In another self-management adaptation, this participant combined prayer with her medication:

**(J) Kamaljeet: *If I am unwell or in pain, if anything is hurting in my body, I have a belief that God will make me feel better. .. In the early morning, I pray to God that today goes ok and I hope that the whole day goes happily.***

**A: *If you have pain, do you actually pray to God for help with the pain?***

**(J) Kamaljeet: *Yes, I pray in front of the God picture and I pray that you are the one that will make me feel better... It affects us in such a way, that the Almighty God will help us to relieve our pain. God makes us feel better... Help us.***

**A: *How does that fit in with what the doctor tells you to do?***

**(J) Kamaljeet: *The doctor gives me tablet. Then I take the tablet. It also helps.***

**A: *So the Sikhism helps and the tablet helps.***

**(J) Kamaljeet: *Yes, yes. Medicines also make me feel better.***



It is evident that Kamaljeet's powerful belief that God would help her to 'feel better', combined with the religious act of prayer, gave her hope for respite in the pain of her condition. Again, there is no evidence that God was implicated in being causal to the development of disease; indeed, Kamaljeet understood God's role to be entirely compassionate, attributing improvements to God. Thus, she used her Sikhism in combination with prescribed medicine, to relieve symptoms. This is further evidence that participants' fatalistic beliefs did not serve to disempower them from effecting positive behaviour changes to self-manage their arthritis.

### **Summary**

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This subtheme has highlighted the participants' multi-faceted physical, psychological, social and spiritual practices, which they select from the abundant self-management palette. These included using prescription medication, in highly tailored combinations with dietary modification, traditional Indian remedies, yoga, and participants' religious practices and spiritual beliefs.

### **Theme summary**

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This theme first revealed the far-reaching psychological and physical consequences of these Punjabi Sikh women's experiences of arthritis diagnosis, then living with the pain and fatigue of OA/RA. Participants' versatile and proactive self-management of their arthritis was then demonstrated. Their highly nuanced experiential accounts showed that all were taking prescription medication, albeit with reticence, in combination with tailored food adaptations, herbal remedies and yoga exercises. Participants' religious practises and spiritual beliefs were further identified as potentially conferring important functions in the self-management of their arthritis. This confirms that the concept of active arthritis self-management is inherently acceptable amongst this group.

#### 6.4.2 Managing tensions

**Table 6.3: 2<sup>nd</sup> Major Theme and Subthemes arising from Study IIIa analysis**

Major themes	Subthemes
<i>Managing tensions</i>	<i>Perceived incompatibilities</i>
	<i>Motivated for engagement</i>

The second major theme of this Study includes reasons that participants' attendance at EPP could not be assured, and that may compromise their engagement with and understanding of its content, so jeopardising the future likelihood of their performing new self-management techniques. Conversely, features which, if present, seem likely to ease Punjabi Sikh EPP attendance, comprehension and subsequent performance of new self-management behaviours, were also elicited.

#### **Perceived incompatibilities**

Combinations of psychological and physical circumstances were identified, which, if present, could jeopardise Punjabi Sikh participants' attendance on EPP. These comprised combinations of psychological and physical incompatibilities, and also practical reasons that could impinge upon participants' ability to attend. Incompatibilities that may undermine participants' ability to understand, engage with the course's content, and thus prevent them from proceeding to perform self-management behaviours, were also identified.

***Psychological and physical incompatibilities*** In the following quote, the participant explained that she felt unable to expend the effort that would be required for her to attend an EPP, due to ill health:

***J: If there is transport provided, do you think if transport is provided, it will encourage people to attend?***

**Varinder: I cannot say anything. I cannot bear botheration... I cannot bear botheration any more...**

**J: It is important if you will share with us that why you are not willing to attend the course.**

**Varinder: I am not keeping very well, so I do not go to do different things. I cannot rush around too much.**

It appears that the potential provision of transport was irrelevant to this participant, hence her unwillingness to comment about it, as Varinder had no intention of attending a course. Her motivation to commit to EPP was compromised by her current ill health. Equally, Varinder may simply not have known enough about the Course to commit, at a time when she understood the exertion of any additional effort, for any reason, to be prohibitive. However, it is noteworthy that the participant was able to attend the women's weekly social group at the proposed EPP venue.

The combination of another participant's perception of her own frailty led to her debilitating fear of falling and injuring herself (previously described), which clearly presented a substantial incompatibility between Harnam and EPP:

**J: There are some self-help schemes for self-management of your health. Have you been or attended any self-help scheme?**

**Harnam: No**

**J: What would encourage you to go onto one, if you are interested? Would you be interested to attend?**

**Harnam: I am frightened in case I fall down. This is my problem. I do not mind going. I want to go. That is why I do not leave home and prefer to stay home in case I fall down.**

**J: You have said that you do not go to these schemes, you fall down. Is there any other reason that you do not go to these schemes?**

**Harnam: [Pause] No, I do not go because of lack of my balance. I prefer to stay home.**

The interest that Harnam expressed in EPP was entirely negated by her fear of falling once out of the house, to the extent that she could not even contemplate attendance. Thus, psychological aspects of Harnam's LTHC

appear at least as debilitating as physical symptoms. However, as with the previous participant, she was able to attend the women's weekly group at the proposed EPP venue, somewhat discrediting her argument. Evidently, there was again some reason that Harnam did not voice. However, this does not necessarily represent a socially desirable response, as both Harnam and Varinder did make their intentions of non-attendance clear, if not their reasons.

**Pragmatic attendance incompatibility** Another incompatibility was between one participant's pre-existing commitments and the time she understood EPP was likely delivered at: Ravinder took her grandchildren to school, then collected and looked after them after school, until her son and daughter-in-law returned home from work:

**AH:** *Would you think about doing something like that [self-management course] if it was available for you?*

**Ravinder:** *Yes, sometimes the time is not suitable, because the last time they did the course [EPP] because I think is erm, only 2-4 something like this – I couldn't take it because I have to get children from school! ...So if it was at a better time, then I might think.*

**AH:** *So if it was in the morning, or?*

**Ravinder:** *Yes!*

**AH:** *Or earlier in the afternoon?*

**Ravinder:** *Yes, yes.*

Ravinder's family commitments took priority over attending EPP, perhaps highlighting her similarity to, rather than difference from mainstream attendees in this respect. The need for appropriately timed courses is confirmed; the impossibility of arranging courses that meet every individual's personal needs is, however, accepted. Whilst only one participant raised this issue, it is reported here as an important consideration – it cannot be assumed that older people are responsibility-free.

However, other participants did not identify pragmatic incompatibilities to attending EPP. For example, in the quote below, organisational practicalities appeared to take precedence over the EPP's precise location:

**A: Where's the best place [for it] to happen?**

**(J) Parmjeet: [Pause] It depends on you, where it's convenient. Where it's easy, where it's not too far. It's up to the organisers where everyone can get together.**

Parmjeet did not express a preference as to precisely where EPP was held, but left this for course organisers to identify, on the criteria of accessibility and proximity. This may suggest that she placed mutual convenience over personal preference, perhaps understanding her peers to have greater barriers than herself. Equally, she may simply not have known of potential venues.

### **Socio-cultural incompatibility**

One participant's perception of EPP was that it may be lacking in cultural competence for Punjabi Sikh attendees in its present format. Mandeep was concerned that the diet and exercise advice that she understood was contained in EPP, would not be culturally-appropriate for Punjabi Sikh:

**Mandeep: Well (pause) most of the Asian women are vegetarian. So if they say 'eat meat', they can't eat meat yes? If they give them the pills with the fish oil, or anything like that, they won't take it. ... Very good for joints, but not for vegetarians – we don't take it! ... Yeah not for vegetarians! And, so, that's another no-go area!! [Laughs] ... And er, if they say swimming, we are not many of us swimmers anyway.**

It appears, interpretatively, that Mandeep may have heard from previous EPP attendees that the Course's content lacked culturally competent diet and exercise advice. Alternatively, she may have been speaking from personal experience of receiving such advice herself, perhaps from her health professional team. Conceivably, Mandeep was simply speculating about what the course might include, understanding that it would be designed from a Western perspective, and may therefore contain irrelevant advice. Mandeep made clear that culturally inappropriate self-management techniques would

not be practised by the women, confirming the need for tailored EPP courses. The issue of cultural differences in food was raised by Jane, in Study I, who recognised this as an area that may require cultural tailoring; Study II highlighted the need for highly refined cultural tailoring.

### **Comprehension incompatibility**

Inherent assumptions in EPP's content, which, in its Biopsychosocial approach, assumes some health literacy, may have represented an incompatibility to one participant's comprehension of the Course. In the following transcript extract, Varinder associated the aetiology and physiology of her arthritis with internal boils and veins:

***Varinder: Neem is good for boils ... there are also boils inside... I think these things are boils inside. Perhaps it will get better. These are boils.***

***J: What other ways do you use to manage your arthritis, so that it gets better?***

***Varinder: I do not use anything else... it is musculoskeletal arthritis, it is in the veins....***

This suggests that Varinder understood that arthritis arises from a biological malfunction within the body, attributing it to an indistinct internal relationship between boils and her veins. 'It is in the veins' is interesting - Varinder may understand arthritis to be vascular, although if she understood the term 'musculoskeletal', this seems unlikely. Interpretatively, she may have understood arthritis to be inherited – Westerners might say 'It's in the genes'. It is also unclear whether Varinder understood that arthritis caused boils, or vice versa, but she had effected a behavioural change by drinking the neem preparation (previously discussed), which addressed her beliefs.

Although this shows that the participant was already self-managing her arthritis, it appears that EPP may not, in its present format, address her needs. This therefore validates Study II participants' concerns (Chapter 5.4.2b) that even the seemingly basic terminology contained in the Course may be beyond

some Punjabi Sikh attendees. Thus the present disparity between participants' health literacy, and the underlying premise of EPP's content, may represent both a comprehension and an engagement incompatibility. However, by adopting another Study II participant's suggestion of conducting taster sessions, it may be possible to attempt to overcome such issues.

### **Summary**

This section has highlighted a number of perceived incompatibilities between these Punjabi Sikh women and EPP, which might adversely affect participants attending performing self-management behaviours. Psychological, physical and pragmatic incompatibilities to these Punjabi Sikh women's attendance were identified, including participants' motivation to attend, emotional response to illness and family priorities. Incompatibilities with optimal participation and engagement with the Course's content, included perceptions of the Course's cultural competence, and tensions between potential attendees' health literacy and the Biopsychosocial premises of EPP. However, many of these potential incompatibilities appear surmountable with sensitive planning. Importantly, no fundamental barrier to the concept of self-management itself was identified.

#### **6.4.2B Motivated for engagement**

The final subtheme resulting from Study IIIa's analysis, contains a number of features which, when present, may help participants willing to attend EPP and engage with its content, so encouraging them to undertake self-management behaviours learned on the Course.

### **Engaging Attendance**

Participants' acceptance of the fundamental concept of self-management itself, is considered likely to facilitate their attendance. For example, in the

quote below, Parmjeet accepted that group self-management courses may be useful to her:

**(J) Parmjeet: I might find some help. You don't know all the answers. You might find it from other people.**

**A: So, that's something you might find helps?**

**(J) Parmjeet: Ya.**

Parmjeet recognised that EPP may serve to increase her knowledge about her disease and its management, and that she could learn from others' experiences. This finding is important as it suggests that the group format of EPP is acceptable to this Punjabi Sikh participant, who wants to discover more about how to self-manage. It also counters the sentiment expressed by one White tutor in the first Study that "... these are people who are more likely to have the necessary support anyway and don't need outsiders coming in and offering them support that they've already got " (Lorraine). I give detailed consideration to the group format of EPP in the next Chapter.

Another participant went further, speculating about what potential benefits she would hope to achieve by attending EPP:

**Nirmal: You know, my health, if I can any clue to get rid of [unclear ?more pain?] (laughs) You know how just when you suffer with these things, it more things that getting down, like cholesterol, tired, heart attack... So if I help it, that many tablets might not have to take.**

Nirmal appeared motivated to improve the physical and psychological symptoms of her comorbid health conditions, and seemed to understand that her illness experiences were, to some extent, inter-dependent, so all might potentially benefit from EPP. It is interesting that she saw effective self-management as a means of reducing her medication intake; this confirms findings presented earlier, around participants' ambivalence to medication. Whilst this appeared to be encouraging her to attend EPP, it also had the potential to lead to Nirmal's disengagement, should the medication-adherence content not address her concerns.



Another facilitator to EPP attendance amongst this group was the convenience of the Course, and the identity of other attendees, as Satanam explains:

**J: What would you think would encourage you and other people to attend these courses? [Pause] ... If there is transport issue, for example?**

**Satanam: If it is like this, there is already a programme arranged, then you can give a talk how to look after your health? It is already arranged in the existing group, then one can attend at that time.**

**J: Sometimes, people say that they will attend, but they do not attend.**

**Satanam: When others are doing it, then you do it with them. It should be arranged like this and .. we can go together and talk to each other.**

This participant understood that convenience and social support were the determinants of her attendance; however, Satanam did not appear willing to consider any change to her existing routine, which may have had implications for her effecting the behavioural changes that are the aim of EPP. Indeed, Satanam suggestion of a talk, rather than a course, implies that she may have been reticent to embark upon anything longer. This highlights an inherent assumption in the question - that the participant would automatically want to attend, if an EPP was organised. However, Satanam appeared to understand that she might benefit from the peer support that a group-based learning environment would offer. It appears unlikely, though, that Satanam could have realised that the scripted nature of EPP would mean that this occurred within defined parameters, or that people whom she did not know may be present.

Furthermore, as her comment about friends is in response to the question of non-attendance, it appears plausible that this participant may not attend an EPP if her friends were not there. It is noteworthy, therefore, that even when preferences are in place (convenient time/location), some Ps simply hold personal preferences not to attend (friends not attending). This highlights the complex and dynamic relationship between internal and external factors that influences the decision-making process. The group-based structure of course delivery was evidently acceptable to this participant, who appeared to welcome the opportunity for social learning, as with Parmjeet, above.

In addition to the identity of other attendees, their gender was also considered. Several participants expressed ambivalence towards the presence of men on mixed-gender courses. However, whilst Varinder had no objection to men co-attending, she suggested they were seated separately:

**J: Ok. If the course is only for females, is it better for you? ... Should it be mixed for male and female or specific for females only?**

**Varinder: ... Yes, mixed can be done...**

**J: No, that's ok.**

**Varinder: I will tell you the truth. Men are our own brothers. One side, men can sit, and the other side, women can sit.**

Varinder proposed gender-divided seating arrangements that she understood would prove appropriate in this setting, perhaps based on her perception of cultural norms within her community. This suggests that not everyone would feel comfortable in mixed-gender groups, again confirming the need for choices to be offered, and close consultation with target communities to be undertaken.

## **Engaging Comprehension**

### **Punjabi language**

Raised in both previous Studies, the issue of language was again considered in Study IIIa. Several participants identified that they would better understand the Course, if it were delivered in Punjabi. For example, in the transcript extract below, Satanam described why the Course would be easier for her if it were in Punjabi:

**J: Ok. For your support of these courses ... should it be in your language? What do you think about this? [Pause]**

**Satanam: If it is in our own language, then it is easier. You understand it fully. If it is in another language, we only understand half and do not understand it fully. It is good for everyone, if it is in our language.**

The question again assumed attendance, which the participant did not contest. It is apparent that Satanam understood Punjabi delivery would ensure

thorough comprehension for all attendees, as her community peers all speak fluent Punjabi. Amongst Punjabi community-members who speak English, Satanam considered that the same depth of understanding of content may not be achieved. This quote contradicts the Study I participant who asserted that " ...these are people who have an understanding when it comes to language, you know, English, plus a second tongue" (Lorraine). This extract therefore again confirms the need for Courses to be delivered in close association with the target community.

Equally, other participants expressed ambivalence to the language of delivery, as in the following example:

**AH: And would be, would that need to be in Punjabi or – I mean your English is superb!**

**Nirmal: Yeah I could do it in both, whatever's easier for you!**

Nirmal's bilingualism meant that neither Punjabi-, nor English-language delivery would affect her capacity to attend an EPP; she would attend whichever was preferential for the course organisers. Nirmal did not appear concerned that she would only partially understand, as raised by the previous participant. This again confirms the need for choices to be available.

### **Engaging new self-management behaviours**

Participants provided insight about how to better encourage people from their community to seek and obtain health educational advice, and what tailored facilities would allow them to practise self-management behaviours. In the following quotation, Ravinder had identified her own need for exercise and understood that some exercises were beneficial and others detrimental to her condition:

**Ravinder: If somebody tell us exercise, maybe we can do it and get better, but that's the problem – because somebody has to tell us 'These exercises are good for you and these things are good for you, these things bad for you'. That's more help we need! ... Then you know! When**

*my pain in my legs, when I go walk, sometimes more pain, then I don't know what to do! That's all. That's when I said to doctor, 'If I know what's good for me then I can help myself!' ... But somebody has to, somebody has to give you information for that!! ... People got diabetes, they can tell you!! Now there's a programme on the radio for that, they can tell you. Not for that thing, not for like everything, 'cos not everyone got the same problem. Cos sometime I got another problem, the other day, same problem but another problem?*

**AH: Arthritis and diabetes, or arthritis and a heart condition?**

**Ravinder: Yeah that's it! So if some place you go and you have advice, you say 'That's the problems I got, what can I do?' then they tell you, I think that might help.**

Acknowledging that she did not have the necessary knowledge, and not wanting to exacerbate her LTHC, Ravinder had sought other sources of health education. Ravinder's motivation and empowerment to attempt exercise in order to self-manage her arthritis would clearly help engage this behaviour. She appeared to conceptualise successful self-management as encompassing both her own and healthcare professionals' collaborative involvement. Yet this participant's frustration with the system that had failed to provide her with the necessary information is almost tangible (and could, therefore, have been included as an 'incompatibility'). Ravinder's understanding that patients' health education needs were fulfilled in certain other conditions is noteworthy, as she evidently had comorbidities, yet apparently only experienced this knowledge deficit with her arthritis. This participant had evidently listened to radio broadcasts about health, but found it only covered individual LTHCs. This suggests that Ravinder was aware that comorbid conditions have varying symptom presentation and treatment implications, and thus had identified that she required more detailed knowledge than the radio programme provided. Again displaying considerable insight and her motivation to learn more, Ravinder had self-identified a facilitator to her tailored educational need, suggesting that EPP could give accurate, personalised advice that included exercise information.

## Summary

This subtheme has confirmed the appropriateness of group-based learning, the motivation to self-manage disease symptoms, and the complex dynamics between convenience and social support, that may assist Punjabi Sikh participants' EPP attendance. The necessity of Punjabi-language delivery to allow engagement with EPP's content for some Punjabi Sikh women with arthritis was confirmed. Finally, the availability of tailored exercise advice that cross-cuts comorbid LTHCs on EPP, may be beneficial to physical self-management.

## **Theme summary**

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This theme highlighted seldom-considered potential incompatibilities and engagement features to these Punjabi Sikh women attending and comprehending EPP. Psychological and physical factors, pragmatics and cultural considerations would represent incompatibilities to some participants' attendance, although sensitive tailoring may overcome these. Features that would further motivate interested participants' to attend, comprehend and subsequently perform new self-management behaviours included an appreciation of group learning, appropriate language of delivery and for individually tailored exercise advice. Thus the acceptability of the fundamental concept of self-management and the appropriateness of group learning is confirmed, as is the importance of cultural tailoring.

## **6.5 Discussion**

This study used rich experiential data to describe Punjabi Sikh participants' psychological and physical experiences of living with OA/RA. Participants' vibrant accounts revealed their diverse self-management practices. Next, potential incompatibilities both to attending and comprehending an EPP, and to performing new self-management behaviours, were highlighted. Finally, features to enhance these Punjabi Sikh women's attendance an EPP, their comprehension of its content, and subsequent performance of new self-

management behaviours were identified. Importantly, no fundamental objection to the concept of self-management *per se* was raised. I now discuss the first major theme's findings around Punjabi Sikh women's experiences of living with and self-managing their arthritis.

### **6.5.1 Discussion of Results**

One participant expressed profound shock at the point of her arthritis diagnosis, which still appeared relevant to her present disease experience. This psychological distress at diagnosis confirms previous findings in cancer populations (McBride et al., 2000), and anxiety and depression in Type II diabetes patients (Eborall et al., 2007). Arthritis research found initially high anxiety and distressed mood in RA patients after diagnosis reduced over the following year in parallel with improvements in clinical status (Evers et al., 1997). In Western culture, highly complex socially contextualised risk perceptions (Pattison et al., 1996), lead to an 'unrealistic optimism' (Weinstein, 1987) of individuals' perceptions of risk of disease. Although extensive research has been undertaken around risk perceptions and optimistic bias with mainstream populations, little evidence appears to have considered whether these processes occur in non-White groups. Whilst impossible to generalise from a single report, this finding may offer some initial indication that such psychological constructs also operate amongst Punjabi Sikh participants; further research amongst BME groups is required.

Another participant's ongoing fear whilst living with arthritis is noteworthy, as it demonstrates the psychological impact of the experience of living with musculoskeletal disease, for this Punjabi Sikh woman. Understanding herself to be too frail to leave home unassisted, this participant had adopted an avoidant self-management strategy to minimise the risk of further fractures. However, although this may have been physically effective, it led to social withdrawal and isolation, which are well-recognised as problems amongst mainstream arthritis patients. For example, in their model of negative emotions,

pain, and functioning amongst chronic pain patients, Tan et al., (2008) found that anxiety directly affected participants' perception of their disability; the authors conclude that targeting anxiety should be incorporated into chronic pain treatment. Sarafino (2002) cited several studies demonstrating serious emotional difficulties experienced by arthritis patients, including feelings of helplessness. Thus, this study's report of one Punjabi Sikh woman's fear accords with the existing literature and suggests it may also be a significant feature Punjabi Sikh people's arthritis experience; further research would be required to determine this. Yet, speculatively, by making specific arrangements to leave the house, with assistance, this participant may have felt that she was exercising control over her life, thus serving to reduce her fear. Turner et al. (2007) conducted focus groups with South Asian subgroups. Participants proposed holding small group self-management courses in community-members' homes, in order to include the most impaired, which would overcome such issues. However, a dearth of research has considered psychological issues amongst South Asians with musculoskeletal conditions, an area that warrants further investigation.

Participants in the present study all reported musculoskeletal pain as a major component of their arthritis experience, confirming the extant literature with White participants from around the world (e.g. Kroenke et al., 2009). Pain that interfered with daily life was found to be higher amongst women, in a large-scale Midlands survey of adults aged >50 years in the general population (Thomas, Mottram, Peat et al., 2007). Guy (2005) found 'biographical disruption', such as that described by this Study's participants, arose from chronic pain. South Asian people have previously reported more regional and widespread musculoskeletal pain than mainstream groups (Njobvu et al., 1999; Allison et al., 2002), with South Asian women reporting more musculoskeletal symptoms than the general population (Williams Bhopal Hunt 1993). Thus, whilst no comparisons were undertaken in the present Study between Punjabi Sikh women and other demographic groups, the present qualitative data offer some preliminary insight into potential similarities of pain experiences between

these participants and White OA/RA patients. Further research that determines what influences this pain experience amongst South Asian women appears warranted, in order that the causes may be addressed.

Other participants' reports of debilitating fatigue confirm previous research in White populations, such as Turner Williams and Barlow (2002), whose participants described fatigue as challenging many aspects of daily living, rendering even basic activities extremely demanding. The issue of fatigue in musculoskeletal populations is recognized as of great importance amongst patients (Kirwan and Hewlett, 2007) and was recommended for inclusion in future RA studies at a meeting represented by patients, clinicians and academics from 20 (mostly north European/American) countries (Kirwan et al., 2007). Women in Canada with OA experienced higher level of depressed mood, greater pain and fatigue than men (Sale et al., 2008). Again, the data in the present study suggest that the Punjabi Sikh women experienced fatigue in broadly similar ways to White participant populations; more research is required to examine South Asian fatigue experiences.

Participants were all taking prescription medication for their OA/RA, albeit with some ambivalence. Again, participants in this study appear more similar than different from mainstream populations in this respect. For example, Gareth Treharne's work examining arthritis medication adherence/compliance/concordance indicates that concerns about the medication including its side-effects, affect rheumatology patients' adherence to taking it 'as prescribed' (Treharne, Lyons, Hale et al., 2006), as reported by participants in this study. Treharne et al. (2006) acknowledge that beliefs about medications are socially and psychologically rooted, and are consistently important for adherence. Horne, Graupner, Frost et al. (2004) examined differences in medication beliefs between 500 UK undergraduate European and Asian students. Students from self-reported 'Asian' backgrounds expressed more negative views about medication than Europeans, perceived medicines as being intrinsically harmful, addictive substances that should be avoided, and



were less likely to endorse the benefits of modern medication. Whilst the results can clearly not be generalised to the present study's participants, the apparent similarity in negative medication beliefs is still notable, and warrants further investigation.

The use of Complementary/Alternative Medicines (CAM) was a notable finding of this Study; I now discuss this with reference to the extant literature. CAM includes various practices that fall outside the dominant biomedical healthcare model and are not usually provided within these medical settings (Bishop et al., 2007). This study's participants' personally tailored combinations of dietary modification and herbal remedies, yoga, religious practices and spiritual beliefs as self-management techniques can all be considered as CAM (Thobaben, 2009).

This confirms previous research amongst British South Asians. For example, the medicinal use of vegetables was found to be an integral part of complex South Asian cultural heritage systems (Pieroni et al., 2007), and traditional Sikh medicines, incorporating food and herbal remedies, were important to Punjabi Sikh females in London (Sandhu and Heinrich, 2005). Dein and Sembhi (2001), Ismail et al. (2005) and Thobaben (2009) found that, as in the present study, CAM was used as an adjunct, rather than an alternative, to Western medicine. Ismail et al. suggested that traditional therapies offered hope that Western medicines were unable to provide, with participants perceiving them as short-term solutions without the toxicity of conventional medicine. The authors concluded that traditional therapies may be effective in psychological coping and stress reduction; the findings from the present Study appear to confirm this. ME people's concerns about medications were noted in Chapter 2.3 (e.g. Horne et al., 2004; Kumar et al., 2008). Turning to CAM use amongst arthritis patients, Taibi and Bourguignon (2003) acknowledged that many individuals with RA turn to CAM therapies. Cross-cultural research with US arthritis patients about their CAM use, found >90 per cent of (White and Hispanic) survey participants had used CAM, although only 13.6% had taken herbs orally and

just 10.1% had tried special diets (Herman et al., 2004). The highly nuanced experiential data presented here support these previous findings regarding the critical significance of CAM in ME people's disease self-management.

Whilst South Asians and arthritis patients, including participants in the present Study, clearly embrace CAM use, great debate continues to surround its effectiveness. The Arthritis Research Campaign (arc) recently produced a summary of CAM evidence for patients, including those with OA and RA, based on data from 40 RCTs. The accompanying publicity material stated "Most complementary medicines have no effect for people with rheumatoid arthritis; picture more hopeful for osteoarthritis patients" and the products that were found to be *least* effective were those listed (**arc**, 2009). However, several points of relevance are contained within it. For example, the active ingredient contained in Indian ginseng, which the current Study's participants reported using (see Box 6.1), has both anti-inflammatory and anti-oxidant properties. Turmeric, also used by Study IIIa participants, can reduce the production of inflammatory proteins that are harmful to the joints (arc, 2009). Ginger, which was widely used amongst Study IIIa participants, inhibits the production of certain types of prostaglandins involved in joint inflammation and this relieves pain and discomfort. Ginger can reduce serotonin release, which plays a role in mood regulation, sleep patterns, concentration and pain perception. Thus it is evident that these substances contain active ingredients that can bestow benefits upon arthritis patients. However, the compounds were administered in tablet/capsule form in the RCTs, not as part of a prepared meal, or tea drink, so entirely overlooking the social context of CAM use in the present participant group. Similarly, given that few South Asians participate in RCTs (Mason, Hussein-Gambles, Leese et al., 2003), it seems unlikely that the report's results would have included South Asian participants, so cannot, therefore, be extended to the current sample.

With little scientific evidence to support the use of traditional Indian dietary modification or the use of Indian herbs, it is apparent that factors other than empirical evidence explain these participants' CAM use. In their literature

review examining beliefs involved in CAM use, Bishop, Yardley and Lewith (2007) found evidence that CAM use as part of LTHC self-management, relates to taking responsibility for treatment and gaining a sense of control and empowerment. This supports the suggestion that these participants' CAM self-management behaviours contributed to their self-efficacy as they felt they were proactively contributing to self-improvement. Griffiths et al. (2005) found Bangladeshis' self-efficacy improved following EPP attendance, indicating that this construct might be beneficial among people from South Asian backgrounds. However, as the self-efficacy measure used in Griffiths' trial had not been validated with this group, more work appears necessary. Encouragingly, Sarkar et al. (2006) found self-efficacy was associated with performing diabetes self-management behaviours in Asian/Pacific Islanders, Black/African Americans, Hispanic, White/Anglo and 'other' ethnicities, with varying health literacy levels. The authors concluded that carefully designed self-management interventions that target self-efficacy may be effective in BME populations with limited health literacy (Sarkar et al., 2006). Whilst the results from these Spanish and English-speaking diabetes patients in the US cannot be generalised to the current sample, it may provide a useful reference point for similar UK studies.

The present Study therefore adds more weight to a growing call for a better understanding of the health-promoting properties of traditional foods and herbal remedies amongst BME groups is required and how this impacts on the use of biomedicine (Pieroni et al., 2007; Sandhu and Heinrich, 2005; Herman et al., 2004). This will assist with routine assessments, treatment planning and future primary health care programmes, whilst

(DeSilva et al., 2008; page 1258)

Participants in the present Study also reported widespread use of yoga to self-manage their OA/RA, in line with previous research in different disease groups.

Yoga is considered to be a feasible intervention for a wide range of cancer patients and survivors (Bower et al., 2005), with cardiac patients under medical supervision (Mamtani and Mamtani, 2005), amongst MS patients (Oken, Kishiyama, Zajdel et al., 2004) and for people with depressive disorders (Pilkington et al. 2005).

Some, limited, evidence supports the effectiveness of yoga in musculoskeletal populations. For example, in their small-scale pilot study, Badsha et al. (2009) reported that 12 sessions of Raj yoga across eight weeks, yielded statistically significant improvements in RA Disease Activity and health assessment questionnaire scores, but not quality of life, compared with the control group. However, the results from 47 IT-literate patients in Dubai are clearly not generalisable to the present study's participants. In another small study, *Iyengar* yoga intervention participants with low back pain, had significantly lower functional disability, pain, and pain medication scores post-intervention and at three-month follow-up (Kolasinski et al., 2005). Again, 44 participants in the US, with a mean age of 43 years, of whom just one control-group member was 'Asian', seem unlikely to be comparable with this Study's sample. Similarly, Sherman et al.'s (2005) study (N = 101) found 12 weekly sessions of *vinnyoga* reduced low back pain symptoms and improved function at 12 and 26 week follow-ups, compared with participants attending a conventional therapeutic exercise intervention, or having a self-care book. However, with a mean age of 44, and 83% White sample (other ethnicities not given), it again appears unlikely that such findings would be generalisable to the present population. The authors observe that it is not known whether the therapeutic benefits of yoga are attributable to the physical exercise, or the mental focus that yoga encourages. In another small-scale US study, 15 OA knee participants performed either traditional stretching and strengthening exercises, *Iyengar* yoga, or no structured group exercise, over a six-week period, with functional 'changes' and quality of life improvements reported (Bukowski et al., 2006-2007). The underpowered pilot study performed by Galantino et al., (2004) suggested that *hatha* yoga may afford limited improvements to balance and flexibility, and depression. Similarly, Williams et al.'s (2005) study of a 16-week *Iyengar*

yoga intervention with 42 participants with chronic low back pain, found reductions in pain intensity and functional disability, and pain medication use at post-intervention and 3-month follow-up.

It is noteworthy that ethnicity was rarely considered (Reid et al., 2008), and ME participants were certainly not targeted, in the above yoga studies, given its apparent widespread use amongst this Study's Punjabi Sikh participants. The lack of high quality well-designed studies is important and should be addressed in future research. However, as many Punjabi Sikh women in the present Study were already routinely undertaking yoga, the extent to which they would further benefit from a yoga intervention seems unclear. Specific yoga exercises, tailored to meet individual's needs, may prove useful. The Findings of this study do, however, clearly identify that yoga presents a useful way in which to culturally tailor the exercise component of EPP.

The strongly positive influence of participants' religious practices around their arthritis experiences are noteworthy, and in line with previous examinations in other ethnic groups. The importance of the participants' Sikhism in their perceptions of their LTHCs, and its important, apparently positive, influence in self-management behaviours, was identified. Some participants in this study understood that God could remove their arthritis pain and that praying would help; thus Sikhism allowed them a degree of acceptance, and afforded an opportunity to become active self-managers. Thus, whilst fatalistic, participants' Sikhism did not render them passive in their LTHC experience, nor cause stigma within the community. The importance of religion in the self-management of chronic illnesses including arthritis, was highlighted by Harvey's (2008) study with White and African American Christians. Participants derived benefits from praying directly to God for help with their health, using prayer particularly to manage pain, as in the present study. Similarly, Wachholtz et al. (2007) suggested that the illness and pain experience in a religious context could encourage feeling closer to God, as feeling loved and supported by a higher power, may mean patients are less likely to "give up" on a task and

continue active coping with pain, potentially increasing pain tolerance. The present study appears to offer preliminary confirmation that this may apply in these Punjabi Sikh women.

This study further appears to confirm Greenstreet's (2006) assertion that the practice of religious ritual can be a source of consolation during ill health, with prayer to converse with God providing a source of coping. Similarly, in their review, Çoruh et al. (2005) found evidence that religious intervention may improve RA, including grip strength, reduction in the number of tender and swollen joints, patient-rated pain and fatigue, and level of functional impairment, reduce anxiety, whilst frequent attendance at religious services may improve health behaviours. The present study provides evidence of the psychological, physical and social benefits that participants derived from their religious practices. The present study offers a small step towards addressing the "large voids" (Powell et al., 2003; p.50) in the literature examining people from non-Judeo-Christian backgrounds. However, Çoruh et al. (2005) introduced a cautionary note: improved health outcomes in religious individuals may be moderated by a large social network, healthier lifestyle, activities supported by the church, or improved coping skills. Thus, the positive effects that the participants in the present Study reported, may reflect the benefits of social support rather than religion. Of particular relevance to this Study's participants, Çoruh et al. (2005) assert that "faith-based partnerships may help an underserved population for which other strategies to improve health have not been documented". Furthermore, an expectation of benefit from prayer, and not prayer itself, may improve health outcomes.

As in the present Study, Ismail et al., (2005) reported that Sikh participants were not passive towards their illness and belief in a divinity did not prevent people from taking active steps to alleviate their symptoms (Ismail et al., 2005). Similarly, Greenhalgh et al. (1998) found that Sylheti-speaking Bangladeshi Muslims with diabetes gave explanations in terms of "God's will", but simultaneously accepted their individual responsibility and potential for

change. The present study confirms these accounts, which are in sharp contrast to the views expressed by Sylheti-speaking Bangladeshi Muslims in Griffiths et al. (2005)'s evaluation of EPP, who saw self-management as futile within the destiny of their Islamic life-course. Religion also appeared to provide a useful distraction strategy for one woman in this Study, when she was unable to attend Temple. The slow passage of time is recognised in patients with musculoskeletal pain, as routines need changing and perceptions of the past, present and future are disrupted (Richardson, Ong and Sim, 2008). People with chronic widespread pain reported a lack of control over time and their bodies in their everyday lives (Richardson et al., 2008), as in the present Study.

The relationships between people's religious and spiritual beliefs on health and illness experiences have been documented. For example, Powell et al. (2003) evaluated a series of selected reviews. The authors suggest that prayer and recitation of mantras *"have a quieting effect that is likely to trigger parasympathetic relaxation, a biologically plausible mechanism for such an association"* (p.42). However, religious/spiritual practices did **not** offer protection against disability, although this may be because religious activities represent a response to increasing disability. Whilst the authors did not comment on the ethnicities/religions of participants in the reviewed studies, they mention "large voids" (p.50) in the literature examining people from non-Judeo-Christian backgrounds. They concluded that a complex relationship between religion/spirituality and health **does** exist, but further investigation is warranted. Such research involving Sikh participants would be especially pertinent in the present study.

Much of the research around spirituality has been conducted with terminally ill patients, with less attention focussed on those with LTHCs, and less again considering South Asian people's perspectives. However, in Harvey's (2008) study, spirituality served as a coping mechanism by providing South Asian participants with comfort, a purpose in life, a means of connecting with others and a sense of inner well-being; clearly, the present study's finding support this.

Friedeman et al. (2002) argue that spiritual health is possible in the presence of serious illness, as it allows the immediate situation to be transcended, and heightens perceptions of the 'wider universal order' over which we have no control. This may account for participants in this Study's apparent acceptance of their arthritis.

Greenstreet (2006) and Greenstreet and Fiddian (2006) identified hope as part of spirituality, which contributes to a sense of future purpose, possibly encouraging alternative ways of coping. 'Generalised hope' is concerned with the 'rather nebulous' (p.64) concept of being present in the moment, whilst 'particularised hope' focuses on goal-achieving 'doing'. Noting that people's cultural background influenced their experiences of hope, the authors described Southeast Asian research in which the essential elements of spirituality centred on the hope generated by the law of karma. Thus the accumulation of meritorious acts would lead to good effect in this life and the next. Indeed, faith can provide hope in the present, whilst future hope amongst the religious is motivated by the 'imagined reality of eternity' (Greenstreet and Fiddian, 2006 p.66). Religion, therefore also contributes to hope, as an aspect of spirituality. The authors suggest that Western cultures may incline toward particularised hope, encouraging control, using information, medicine and technology, whilst Eastern cultures may focus on generalised hope, using meditation and reflection on past experiences to gain confidence in dealing with difficulties of living with a LTHC (Greenstreet and Fiddian, 2006). Thus, it is evident again that EPP may, for some, not be culturally competent, although it seems plausible that South Asian attendees could choose, for example, meditation as their Action Planning target, so blending the two proposed constructs of hope proposed by Greenstreet and Fiddian, to transcend the challenges faced in their health.

In one study which qualitatively examined Punjabi Sikh spirituality and health, Labun and Emblen (2005) conducted interviews with English-speaking Punjabi Sikh participants in Canada, who understood that they had to take care of



themselves within God's predetermined parameters. Labun and Emblen (2005) highlighted the delicate balance between religious practices, spirituality, and health. Punjabi Sikh participants understood that religious practices led to spiritual strength, which was inextricably linked to both healthy mind and body. This interplay between these related facets of the Punjabi Sikh women's daily lives with arthritis, is also clearly discernible in the present Study, therefore supporting Labun and Emblen's (2005) findings, amongst this group of Punjabi Sikh women in the UK.

I will now discuss the second major theme, which identified tensions between the Punjabi Sikh women and EPP. Regarding incompatibilities around participants' EPP attendance, it was evident that one participant's health status was an issue. Psychological factors experienced by another in relation to her LTHC precluded her attendance; another had family commitments that took priority. Whilst reasons for non-attendance are not widely reported in the self-management literature, this is starting to be addressed; it appears that participants in the present Study may be more similar than different to potential EPP attendees in mainstream communities. For example, Bancroft, Barlow and Turner (2004) and Barlow et al. (2009) reported the reasons for non-attendance on CDSMC as inconvenient venue, illness and inconvenient time of the Course. Examining differences between attenders and non-attenders, Barlow et al. (2009) found that 'informed non-attenders' on a CDSMC were older, had longer disease duration and were less anxious than those who chose to attend. In the US, participants cited physical symptoms as an access barrier (Jerant et al., 2005), with the authors noting that the burden of self-management is heavy for people with multiple LTHCs. In another qualitative US study with predominantly White participants, logistical issues, physical limitations, the emotional impact of disease, and the overwhelming effects of dominant individual conditions, were identified as barriers to self-care (Bayliss et al., 2003). Both studies established that transport was an issue; the current study did not find this, as the proposed location of the EPP was known to be convenient to potential attendees. Equally, it is acknowledged that the participants' expressions of incompatibility with the Course could indicate that they were simply not yet ready to

undertake behavioural change in relation to their arthritis, suggesting that they were in a pre-contemplation Stage of Change (Prochaska and diClemente, 1984, in Barlow et al., 2002). Finally, it is essential to note that every participant had the right to choose non-attendance.

I now consider incompatibilities with participation and comprehension of the EPP. One participant recognised that the Course may not be appropriately tailored, for example around vegetarian dietary habits, whilst another participant's comments highlighted the need for the assumptions around EPP attendees' health literacy and the course's medical content to be examined. Healthcare provision that assumes users have Western attitudes, priorities, expectations and values, and that they understand the organization of public services, can be considered to be institutionally racist (Atkin 2004). Thus, it could be argued that the Western model of current EPP delivery forms the barrier, rather than the beliefs held by Punjabi Sikh participants. The necessity for EPP to be culturally competent, by addressing the issues participants raised in order to deal with the needs of this South Asian population, would counter such an allegation. This confirms previous research, for example, health interventions with ME populations that have been designed to take into account cultural beliefs and values also increase the likelihood that health messages will be heard and heeded (Brach and Fraser, 2001; Samanta et al., 2009). Brach and Fraser (2001) suggest that the use of community health workers from the same communities that they serve, can modestly improve access to and utilization of health care. Thus the provision of a Punjabi Sikh EPP tutor to deliver a tailored course, could encourage attendance amongst the present Study's participants. In order to overcome the participant's perception that EPP is insufficiently tailored, taster sessions could be delivered prior to enrolment – as suggested by Karamdeep in Study II - to highlight its relevance and so encourage South Asian community-members to attend. This in turn may encourage word of mouth recommendations and so improve EPP uptake amongst this South Asian group.

Whilst the Biopsychosocial and traditional Indian approaches to arthritis representations seem to be dichotomous and therefore mutually exclusive, there appears to be sufficient commonality of understanding to explore potential solutions to this. Both understand the biological/physical underpinnings of disease and understand that the consumption of various medicinal substances can confer benefits; this Study has already established that self-management is conceptually acceptable amongst this group. Adopting a "bottom-up" approach to sensitive CC tailoring may be beneficial, working with South Asian participants to identify areas of commonality within the two domains, and using these to build upon the relative strengths of each approach. Caution would need to be exercised to avoid assuming Biopsychosocial Model superiority, which could lead to disengagement with EPP amongst Punjabi Sikh attendees. The inclusion of details about such cultural tailoring could then be incorporated into the proposed taster sessions and publicity materials.

Many participants already seemed motivated to attend an EPP, and features that would help with their engagement in terms of attendance and comprehension will now be discussed. Participants' perceptions that self-management education could improve their health, reduce pain, and that they could learn from others in a group setting, is encouraging. This broad acceptance suggests that self-management is conceptually satisfactory to this small group. In their RCT of EPP for Bangladeshi Muslim Sylheti-speakers, Griffiths et al. (2005) reported findings consistent with an acceptance of self-management, including improved self-efficacy, which the authors suggest may have led to increased use of their self-management skills. However, as previously mentioned, this finding did not apply to non-attenders (Griffiths et al. 2005). Thus, this finding may suggest that EPP for these Punjabi Sikh women with arthritis may encourage active self-management, but confirms that it cannot be generalised.

International cross-cultural evidence examining lay-led self-management education delivered to ME groups, is also largely encouraging. For example Lorig et al. (1999) found Hispanic attendees benefitted from the Spanish-language ASMP. Likewise, in *Australia*, Walker et al.,(2005) conducted focus groups with Chinese, Vietnamese, Greek and Italian immigrants, and found self-management to be conceptually acceptable, whilst literacy was identified as a probable barrier. Following delivery in these communities' languages, attendees had significantly higher scores than controls on energy, exercise, symptom management, self-efficacy, general health, pain, fatigue and health distress (Swerissen et al., 2006). Similarly, Study I in this thesis found that White tutors who had delivered EPP to English-speaking South Asian attendees in Coventry, identified hypothetical barriers that were not actually experienced during delivery (Hipwell et al., 2008). Thus, participants' positive responses about self-management education in the current Study, in the presence of the anticipated EPP tutor, cannot be assumed to entirely represent a social response bias; I return to this in 'Caveats'.

One participant was enthused at the prospect of EPP having the potential to lower her medication intake, with this perception apparently motivating her to attend. This is not an objective of the Course, which actually highlights the importance of medication in the self-management of LTHCs. This finding again confirms the need for pre-enrolment taster sessions, as previously discussed. It further highlights the medication-adherence section of EPP as another area where highly refined design and delivery, to ensure it does not disengage motivated participants by imposing the dominant model upon them. Thus, the need for culturally competent tailoring, that adequately Punjabi Sikh addresses attendees' concerns is again confirmed.

The presence or absence of men on any EPP was unlikely to be problematic for these participants – no-one objected to mixed-gender groups. This perhaps contrasts with stereotypes about South Asian men and women feeling uncomfortable in each others' company, or requiring gender-divided services.

This may reflect a unique finding amongst these particular Punjabi Sikh women, or, if found to be held amongst others from similar backgrounds, may represent a notable difference between this South Asian group, and others, so highlighting the heterogeneity within and between different South Asian cultures. Whilst this does not answer Jane's concerns from Study I "*do they object to sitting next to lady, or a lady to a man that's not of their own culture?*", as that rhetorical question was asked in relation to ethnicity-specific EPPs, it does clarify the situation for this group of Punjabi Sikh South Asians. This finding also illustrates that within the complexities of CC healthcare provision, simple solutions may be readily available; the need for meaningful user involvement in service design and delivery is again confirmed.

A convenient location for the Course would also engage these women to attend EPP. Some participants' inability to identify the potential venue of EPP likely reflects a lack of knowledge about suitable locations. Given that the current meeting place at the Gurdwara's community centre was identified as a suitable location earlier in this Chapter, this appears to offer a simple solution.

In terms of engaging the women's comprehension, the need for courses to be delivered in Punjabi was confirmed in the present Study. This accords with previous research around patient education with South Asian communities, and confirms the perception of the White and South Asian tutors interviewed in Studies I and II. As previously highlighted, mere linguistic translation would fail to address the complexities of the issues addressed by EPP in the cultural context of self-management amongst South Asian women. Culturally sensitive tailoring of the course is required (Samanta et al., 2009; Brach and Fraser, 2001; Adebajo et al., 2004; Greenhalgh et al., 2005). It is also noteworthy that, whilst not asked explicitly about working with interpreters, no Punjabi Sikh participant suggested this as an alternative, as raised by Study II tutors. Similarly, nobody highlighted the need for the formality of the Punjabi to be addressed. However, this may simply reflect that participants were unaware that these were potential options

being considered. Conversely, whilst Punjabi-language delivery was crucial for some participants' comprehension of the course, others' bilingualism meant that English-language delivery would still be acceptable to them. This highlights the need for choice to be offered to potential attendees where possible, without assumptions being made about language preferences. Such choice may represent one element of cultural competence, thus avoiding accusations of institutional racism in the delivery of EPP (Atkin, 2004).

Finally, I consider a feature of EPP that one woman identified, that would further her motivation to performing self-management behaviours. The provision of individualised tailored information about exercise on EPP, would facilitate one participant's exercise self-management behaviour; however the logistics of this for up to 16 attendees on an EPP may prove unworkable. 'Signposting' to healthcare services is routinely included on EPP, however, which may serve to address this participant's suggestion. This woman's use of radio as a source of health education resonates with the Study II finding that television may represent an untapped medium. The use of such media for health education, EPP awareness raising, or advertising has not apparently been considered before.

### **6.5.2 Limitations**

A number of caveats in Study IIIa need to be addressed. The prevalence of self-management behaviours amongst members of this community group, prior to their attendance on EPP, may reveal an in-group norm, rather than a reflection of wider self-management practises amongst Punjabi Sikh women. This would suggest a sampling bias; in turn their active self-management may limit the potential benefits they could obtain from the course. Research with Punjabi Sikh from other locations would identify whether the self-management behaviours reported are likely to be more widely generalisable. In turn, this could lead to a meaningful self-management intervention designed to complement the health beliefs and behaviours of these groups.

As participants in the present Study knew that the interpreter was also the EPP tutor, there is a likelihood of socially desirable answering to these questions. Whilst this highlights a design flaw of the current study, this pragmatic choice was unavoidably made to facilitate my access to this Punjabi Sikh group, which ensured the interviews were undertaken; no other interpreter had been identified, and the other Punjabi Sikh tutor was unavailable to assist. Furthermore, it underlines the scarcity of the highly skilled staff that are indispensable in collaborative, complex cross-cultural research. It confirms the pivotal role of interpreters, which I fully acknowledge here (Wallin and Ahlström, 2002; Pitchforth and van Teijlingen, 2005; Fontes, 2008). This study's methodological dilemma supports Porter's (2007) assertion that meaningful, applied, qualitative research requires a realist approach to validity. Indeed, rather than producing biased responses according to what participants believed the interpreter/EPP tutor expected them to say, it is possible that they could have used the interviews as an opportunity to address any concerns, thus perhaps providing richer data than would otherwise have been generated. Given that some participants openly stated that they had no intention of attending EPP, any socially desirable responses were not universal.

Similarly, socially desirable answering could have arisen because my ethnicity differed from that of participants', and the sensitive nature of the topic of investigation. It is possible, for example, that participants may have displayed demand characteristics and given 'politically correct' responses, (e.g. perhaps telling me what their religious teachings say about illness, rather than their personal beliefs). However, participants' right to confidentiality was stressed prior to, and throughout the interviews as necessary, to assure participants that they could speak freely. Given the diversity of answers, such a response bias does not appear to have compromised the current study. Indeed, participants appeared genuinely pleased that their needs were being addressed, and were keen to share their experiences and understandings with me.

Another consideration is that many of the recommendations that arose from these interviews, may not be workable in practice, given financial and time

constraints for EPP's implementation. Should any of the suggestions be implemented, then efficacy/effectiveness studies would be required. Thus, like Study II, Study IIIa may again represent an academic exercise in ideology. These participants' experiences of living with arthritis, and self-management of it, following EPP, will have been influenced by numerous factors other than their ethnicity, for example their educational level, and experiences of poverty. Thus, the findings reported here cannot be assumed to be directly attributable to participants' Punjabi Sikh culture alone, but rather a reflection of their multi-faceted life experiences, including cultural influences.

Whilst the Punjabi interviews in Study IIIa enabled some Ps to express themselves in a way which would not have been possible in English, I lost ability to probe, consequently feel some depth of data was compromised. Some points were not explored or explained in detail, as the same-ethnicity interviewer understood the cultural context, and therefore did not probe. Although I was present, I was not asked for clarification at any point. For example:

**J: How does God help you to get better?**

**P: I recite God's name and go to the Gurdwara. At home, I recite God's name. That is it. [Pause]**

**J: How did you feel when you were well, before the pain?**

**P: It was fine before...**

This highlights the lost opportunities for detailed questioning that the participant's response presented around both her home prayer habits, and also around her Gurdwara attendance. However, opportunities for probing that were missed during the interview also happens when I conduct interviews. This is not intended as a criticism of the interpreter, who could not be expected to understand my perspective, and without whom these data would not have been collected. It was for this reason that three-way interviews were conducted with those participants in Study IIIb who chose to be interviewed in Punjabi. The central importance of the roles of interpreters and translators were detailed in Chapter Three and I return to them in Chapter Eight; I acknowledge



that differences in meanings of concepts may have compromised the linguistic equivalence of the translated data on which my analysis was based. However, these Findings provide evidence that IPA studies with interpreters and translators are justified if the benefits from speaking to a specific group outweigh the costs from not speaking the same language, (Smith, 2004). Finally, I again accept the Findings represent my own interpretations of the data; alternatives may exist.

### **6.5.3 Strengths**

Study IIIa also has a number of strengths. The highly detailed experiential descriptions have provided stimulating insights into these Punjabi Sikh participants' understandings of living with and self-managing arthritis. This appears to fulfil Smith (1999)'s argument that qualitative research should be judged primarily on how illuminating it is of the particular cases studied and that the 'micro-level theorising' should be richly informative of those particular individuals. This study has highlighted potential areas that require careful consideration to ensure the Punjabi Sikh women's engagement with EPP and future performance of new self-management techniques, confirming the applied nature of the study which may contribute to its validity Yardley (2000, in Langdridge). The purposive, "time-venue-based" sampling technique (Crosby et al., 2009) adopted for use in the present Study has proved an effective recruitment strategy and may be useful to other researchers in future. Similarly, the rigorous approach to ensure accuracy of translations may serve as a discussion template for further development. Believed to be the first academic Study of its kind with Punjabi Sikh women, the Findings reported therefore all represent novel contributions to knowledge. The highly individualised nature of Ps' culturally-tailored self-management practices, and facilitators and incompatibilities with EPP have been identified. Use of IPA on translated data is also believed to be methodological innovation. Whilst not intended to be generalisable, this study may, however, represent a useful starting point for future research in this area.

## 6.6 Chapter Six Summary

This small-scale, in-depth, study has identified that these Punjabi Sikh Indian women experienced arthritis as having severe psychological, emotional and social ramifications on their daily lives. Participants' were highly versatile in their proactive arthritis self-management, with techniques encompassing refined combinations of prescription medication, traditional Indian CAM, and religious and spiritual expertise, tailored to their individual needs. These interviews revealed that Punjabi Sikh participants were motivated and empowered to effect positive behavioural changes in order to self-manage their arthritis. The psychological, physical and pragmatic incompatibilities with EPP attendance that were identified, do not appear insurmountable, for example, with 'taster sessions' to help resolve potential misperceptions. However, sensitive, culturally competent, consideration of Punjabi Sikh women's low literacy and health literacy is required in order to ensure that the underlying assumptions of the EPP do not preclude attendees from engaging with the content. Features likely to help the Punjabi Sikh women engage with EPP included an inherent acceptance of self-management, the necessity of a convenient venue with delivery in Punjabi, to allow tailored self-management education that is meaningful to attendees. Group self-management education, such as EPP, thus appears inherently acceptable to this sample of Punjabi Sikh Indian women.

It was decided to perform follow-up interviews with these participants, after their attendance on a Punjabi-language EPP, to examine their experiences of the course, and subsequent self-management behaviours.

# Chapter Seven: Study IIIb

***" My leg is better than before... exercise"***

*Punjabi Sikh women post-EPP attendance*

## Chapter Contents

### 7.1 Study IIIb objectives

### 7.2 Recruitment and Participants

### 7.3 Data-collection and Analysis

### 7.4 Findings

### 7.5 Discussion

### 7.6 Chapter Seven Summary

#### 7.1 Study IIIb objectives

The previous Chapter revealed the Punjabi Sikh women's severe psychological and physical arthritis experiences, and empowered self-management practices and influences, in their daily lives with arthritis. Perceived incompatibilities between the women and the course, and features to improve the participants' EPP attendance, and their engagement with and comprehension of it, and their performance of self-management behaviours were highlighted. It was apparent that Punjabi Sikh participants' experiences of attending the translated version of EPP, delivered in Punjabi, would provide invaluable evidence into their perceptions of this SM educational intervention. The objectives of Study IIIb were, therefore, to:

- 1. From the perspectives of Punjabi Sikh women, describe the experiences of attending a Punjabi-language EPP course;**
- 2. Describe their subsequent experiences of living with arthritis;**

**3. Identify barriers and facilitators to self-management practices, including attendance on EPP, among women from Punjabi Sikh backgrounds.**

## **7.2 Participants and Data-collection**

### **7.2.1 Recruitment**

The purposive, pragmatic sampling that had necessarily been employed in the previous Study had produced a sample of 10 Punjabi Sikh women participants, who lived with osteoarthritis or rheumatoid arthritis. Of these, four participants had attended the Punjabi EPP. The BME EPP Lead telephoned the four women, and all agreed to be interviewed, at the same community location as in Study IIIa, in the same "time-venue-based" sampling technique (Crosby et al., 2009).

Study IIIa participants who did NOT attend the Punjabi EPP, gave their reasons as 'not well', 'in India', 'do not understand Punjabi', 'abroad', 'child-minding granddaughter' and one Study IIIa participant attended EPP the first week, but then fell and therefore could not attend in subsequent weeks. Expertise within the research Team indicated that follow-up interviews with non-attenders rarely obtained insight beyond the initial explanations for non-attendance stated. The six Study IIIa participants who chose not to attend EPP were not, therefore, interviewed in Study IIIb.

### **7.2.2 Participants**

The four female Punjabi Sikh Indian participants were aged 66 – 68 years, and all had OA and comorbidities including cardiovascular disease, hypertension, and diabetes. Participants gave the language that they spoke the most as Punjabi, with other languages spoken including English and Hindi. In the transcript extracts presented in the Findings of this Study, all participants have the same pseudonyms as in the previous Chapter.

### **7.3 Data collection, Translation and Analysis**

Informed consent for both pre-EPP and post-EPP interviews was obtained from every participant prior to Study IIIa, in the language of their choice. This was available for participants to re-read and raise any questions, prior to the commencement of each interview. As this 'planned' longitudinal data-collection (Flowers, 2008) was negotiated at the start of Study III, participants were all aware of my intentions to conduct interviews with them, following their attendance on EPP. There seems little scope, therefore, for misunderstandings arising from participants wondering if they gave the 'wrong' answers within the first interview (Flowers, 2008). Recruitment again used the "time-venue-based" technique (Crosby et al., 2009), in which participants were approached in their usual meeting-place at the social group they attended weekly at the Gurdwara. Interviews took place 4-5 months after participants had attended, as is usual in short-term studies exploring SMP attendees' experiences (Barlow et al., 2002; Taylor et al., 2009). All interviews were digitally recorded, with participants' consent.

#### **7.3.1 Data collection**

##### **Punjabi and English bilingual data-collection**

Three participants asked to be interviewed in Punjabi. Three-way interviews were performed, as this allowed my continued input throughout data-collection, such as probing in response to participants' answers. The process was the same as that described in Chapter 6.3.1. As JS, the BME lead, had delivered the Punjabi-language EPP to participants, it was inappropriate for her to interpret the interviews, as participants may not feel able to speak freely about any concerns they had regarding the course. Another trained, qualified, NHS interpreter, was therefore engaged, and interpreted the three interviews with Punjabi-speaking participants.

A meeting was arranged at the University, for me to brief the interpreter about the aims of the study, and for us to discuss how best to achieve these. I

emailed a copy of the interview schedule (please see Appendix 3.6.1) to the interpreter prior to this meeting, so that she could raise any issues or concerns, prior to translating it into Punjabi (please see Appendix 3.6.2). We agreed a consecutive interpreting style, with the interpreter performing an active role during the interviews, and a triangular seating arrangement, in accordance with Wallin and Ahlström (2006). The interpreter and I had agreed that the conceptual equivalence of cultural meanings should be the primary aim of her interpretation during the interviews, in accordance with Birbili (2000) and Tribe (2007). No issue was raised concerning the interview schedule's content. The interpreter's pivotal role in the research process, and her subsequent impact on the findings are explicitly acknowledged - however, by meeting to discuss some common issues around interpreting, I hoped to mitigate any potential serious problems. Immediately following each interview, the interpreter and I held an informal debriefing session, discussing any area of potential concern or particular success, in order to be as responsive as possible to the participants. I return to this in the Discussion.

### **English language data-collection**

I conducted one interview with a participant who indicated that she wanted to be interviewed in English.

## **7.3.2 Translation and transcription procedures**

### **Punjabi interview data**

The interpreter had also agreed to translate and transcribe the three Punjabi transcripts, following the interviews. The interpreter translated and transcribed the interviews from the audio-files straight into English. A research-trained, fluent Punjabi-speaker was employed to validate the accuracy of the translated transcripts, using the audio files and the English transcripts. As it was not possible to arrange a meeting between the interpreter and the validator, the 'track changes' function of Microsoft Word was used by the validator to

highlight any areas where discrepancies may have occurred (7.4 Findings, below, provides examples of this and I address this in 7.5 Discussion). The interpreter and validator were both paid the appropriate hourly professional rate for this work.

### **English interview data**

I transcribed the English-language interview verbatim, line-numbering the transcript prior to analysis, as in the previous Studies.

#### **7.3.3 Ethical considerations**

Issues around participant and researcher safety were again addressed as in previous Chapters. Coventry University Ethical Committee approval was obtained before commencement of the study (please see Appendix Two). No physical or psychological harm was expected to occur as a result of this Study. In order to protect participants' identities, and in order to assure continuity for the reader, the pseudonyms allocated during Study IIIa are used throughout this Chapter.

#### **7.3.4 Analysis**

My analysis of the translated and validated (where appropriate) English transcripts used the IPA approach as previously described. Where the validator had alerted me to discrepancies in interpretation/translation of the Punjabi interviews, I was able to exercise caution and judgement in my analysis of these data, so ensuring that only participants' experiences were analysed, rather than the interpreter/translator's perceptions of these. (7.4 Findings, below, provides examples of this and I address this in 7.5 Discussion).

#### **7.4 Findings**

As Table 7.1 shows, the analysis of the four transcripts of the interviews that were conducted after participants had completed the Punjabi EPP, identified two major themes, comprising five subthemes.

**Table 7.1 Major themes and Subthemes arising from Study IIIb analysis**

Major themes	Subthemes
<b><i>Punjabi Sikh EPP attendance experiences</i></b>	<i>Attendance Compatibility</i>
	<i>Design concepts</i>
	<i>Cultural competence</i>
<b><i>Punjabi Sikh Post-EPP self-management experiences</i></b>	<i>Physical</i>
	<i>Psychological</i>

These are my interpretations of the data; I accept that others may exist. These will now be examined in turn.

#### 7.4.1 Punjabi Sikh EPP attendance experiences

**Table 7.2: 1<sup>st</sup> Major Theme and Subthemes arising from Study IIIb analysis**

Major theme	Subthemes
<b><i>Punjabi Sikh EPP attendance experiences</i></b>	<i>Attendance Compatibility</i>
	<i>Design concepts</i>
	<i>Cultural Competence</i>

In the first major theme of this Study, participants identified a number of factors that influenced their decision to attend the Punjabi-language EPP, which are described in the subtheme *Attendance Compatibility*. This theme then highlights features of the course's *Design Concepts* that participants commented on, before considering specifics of the delivery-format and the content that contributed to its *Cultural Competence*.

#### Attendance Compatibility



Participants recalled a number of features that they considered, when assessing whether or not they were going to attend the EPP. In the following extract, the participant describes what encouraged her to attend EPP:

**AH: I wondered what made you decide to go on the course?**

**I: She is saying that how did you decide that I want to do this course? Tell us about this?**

**Parmjeet: It was free, I thought to do this course, there is J, I heard from her**

**I: She thought that she was free, you know, so why not do this course when she heard about it**

**AH: HUU, HUU.. So was it a convenient time or?**

**I: She is saying was the time convenient, was it ok?**

**Parmjeet: It was on the same day, It was on Monday, it was on the same day**

**I: They come here, you know. They come here every Monday to the Temple so it was convenient for her to attend the course**

**AH: I see, huu, I see, did the fact that J was leading it that helped you to decide?**

**Parmjeet: Ya**

**AH: If it was somebody else, it was not J but it was still here, might you have done it, what do you think?**

**I: She is saying that if it was not J and it was someone else here, would you still have done the course?**

**Parmjeet: Ya**

**I – She would have done it anyway**

**Parmjeet – Ya**

**AH: The place is more important than the person?**

**I: That the place is more important than the person**

This participant valued the fact that she was not charged for attending the EPP and was further influenced by the personal approach by the same-ethnicity course tutor, who the participant already knew. However, the convenience of the location was the deciding factor. With no change required in Parmjeet's

routine, as the course was held at the same time as the social group usually meets, she was able to attend with minimal inconvenience. It is evident that inter-related social and environmental (external) factors that were beyond Parmjeet's control, such as the initial invitation and the Course venue, encouraged this participant's EPP attendance.

It is interesting that in Study IIIa, Parmjeet did not express a preference as to precisely where the EPP was held, but left this for the organisers to identify, on the criteria of accessibility and proximity to attendees. Similarly, in the previous Study, Parmjeet thought it inappropriate for doctors to deliver EPP, as she considered they would be too busy, and was otherwise unconcerned about who delivered the Course. The present Study has identified that the convenience of the Course to coincide with her usual routine were pivotal factors in Parmjeet's decision to attend, suggesting that these features may be of more consequence to her than she realised. The quote, above, confirms that the identity of the tutor was not vital for this participant, as she had stated in Study IIIa; similarly, another Study IIIa participant (Mandeep) expressed no preference as to lay- or health professional-led courses. Taken together, the two studies indicate that these Punjabi Sikh women were open-minded about who delivered EPP.

When asked what had encouraged her to attend EPP, another participant cited curiosity both about the Course's content, and also about claims that arthritis patients experienced improvements in their condition, following attendance:

**AH: Why did you go on it – what made you decide? Can you remember?**

**Nirmal: One: curiosity – what they do there, what they teach there, and because they told me arthritis patients suffer much less after, some things like that.**

Nirmal's response suggests that she was motivated to learn more about what EPP entailed, in order to potentially improve her own health, representing internal, psychological facilitators. This is in contrast to the previous participant, whose attendance was largely governed by pragmatic, external considerations.

It was Nirmal, in Study IIIa, who described arthritis pain as analogous to a hammer blow. This perhaps provides some insight as to why she was so highly motivated to attend, given that she was also aware of the positive benefits experienced by previous attendees with arthritis: to reduce the pain that she experienced. The previous interviews also identified that Nirmal understood that her comorbid LTHCs were inter-dependent, and she appeared motivated to improve her symptoms; this may have further contributed to her curiosity.

### **Design Concepts**

Several features of the inherent design of EPP appeared to be acceptable amongst these four participants'. In the following quote, for example, Nirmal described the benefits that she derived from the group peer support, which took place in a confidential environment:

***Nirmal: Because we can talk freely and we are still bound – it doesn't go beyond these four walls. So we would talk freely. We all had problems. There was nobody there without problems. So everybody was listening to each other. Yes. Well you can't talk to anybody in there [indicates towards main social room of Centre] (laughs)!! Small numbers – then you can talk!***

The participant understood that being confidentiality-bound increased her own, and others', ability to speak candidly about the difficulties they faced in living with a LTHC. In this quote, Nirmal demonstrated the effectiveness of the group environment afforded by EPP, as it generated mutual understanding through shared experiences. In Study IIIa, a different participant acknowledged the psychosocial benefits of interacting with her peer-group, which alleviated her anxiety and social isolation, whilst providing pragmatic

support in terms of arthritis treatments. The current extract therefore provides a link between these two phases of Study III. The structured nature of the small-group, focussed discussions of EPP appeared to serve a more productive function than the generic problem-sharing that Nirmal's routine weekly social group provided. Accordingly, it seems likely that the social support and focus for change afforded by the confidential, structured, group format of EPP may be suitable for Punjabi Sikh Courses, based on this finding.

Another participant also appreciated the group-based Course structure, but for slightly different reasons: it afforded the opportunity for group learning to occur:

**AH: Did you have favourite part?**

**I: She is saying the on the course did you have any favourite part that you liked?**

**Varinder: We liked it because we were meeting each other... we went there.. so. We were listening to others' ideas which were good.. someone was saying something about the body**

**I: Hmm, she is saying that .. you know that they used to enjoy the course because there were all different ladies who had different problems\* and when you know and how they used to manage. Different ideas from other people. Ya, other people's idea**

**AH: – Other people on the course**

**Validator's note:**\* Participant does not mention the different problems- what the participant says is that she liked to listen to other people ideas about their health

Whilst I asked Varinder about her favourite element of the Course content, she responded about its format, which may suggest that the group interactions were of more interest to her than the tutor-led sections. Varinder clearly identified that listening to her peers' self-management ideas was beneficial to her; the interpreter's addition of 'different problems' has not been analysed. The informal social learning of self-management ideas was clearly visible amongst Study IIIa participants, and this quote confirms the inherent suitability of a formal social learning approach amongst these Punjabi Sikh attendees. It is important to note that, as with the previous participant, it was not merely the

social occasion of leaving home and interacting with friends that she liked, but the focussed nature and content of discussions. Varinder's comment regarding learning about the body is also interesting, suggesting that she found this useful, whilst somewhat negating the Study II tutor who considered that elderly Punjabi Sikh people may be unused or unsuited for such education.

Another facet of the EPP's design that encouraged participants' engagement with the Course, was the opportunity for social comparison, as this quote demonstrates:

***Nirmal: And you think 'Oh I got nothing – it's only arthritis!' [laughs] 'That's all!' [laughs]. So it's real encouragement, looking at each other. And you see people's problems that people got are more people are worse than me and they are coping, so why can't I?***

It is clear that Nirmal came to understand that her arthritis was not as debilitating as some attendees' LTHCs, thus putting her own physical problems into perspective, and perhaps enhancing her acceptance of her condition. Comparing herself with others who Nirmal perceived were coping better, evidently also catalysed her hope for her future. This quote therefore demonstrates the effectiveness of the upward and downward social comparison element of EPP. Taken with the previous quote, and the relationships identified with Study IIIa findings, it appears possible to draw a tentative conclusion that the EPP's recognised psycho-social format may be appropriate for this Punjabi Sikh population.

Participants also responded favourably to the Action Planning element of the Course. In the quote below, for example, Mandeep had evidently embraced Goal Setting and Action Planning, applying it to the exercise component of EPP (which I return to in detail shortly):

***Mandeep: Yes..... it was like this... Tasks being set and completing those tasks felt good. Walking or whatever task was set at that time we had to do it. This felt really good***

The pleasure of her success at achieving the planned activities, further encouraged Mandeep to complete additional walking tasks. This suggests that positive emotions may serve a useful function for Punjabi Sikh women in this context. This is also preliminary evidence that the skills mastery process, a feature of Self-efficacy Theory included in EPP's design, may have promoted an affirmative sense of accomplishment at meeting her small, graded, achievable targets, which further boosted Mandeep's motivation. As Action Planning is generalisable beyond the health arena, this represents an important finding that may benefit attendees in other areas of their lives. Given that the South Asian tutors in Study II had experienced substantial difficulties with elderly Punjabi Sikh participants understanding Action Planning, however, caution should be exercised when interpreting this finding, which may simply reflect one person's position.

Yet ill-health meant that not all attendees were able to achieve active goals; nevertheless they evidently understood that achieving even a small pre-determined task, was adequate:

***Nirmal: There were some [not] doing it [Action Planning] because they were saying that they were not well – and they were unable to do it, one friend was saying that my garden flowers are so beautiful so I will sit and watch flowers. It is nice!***

This suggests that even the less able attendees were afforded an opportunity to accomplish small goals, which they could then report back to the group as a success. The gratitude activity that this participant's friend performed, also benefitted Nirmal herself, as she derived pleasure from the positive experience that she shared with her friend. Again, shared success is a design feature of EPP that appears to be relevant to this Punjabi Sikh attendee.

Two elements of the EPP that appealed to one participant were the care extended by the tutors, and the Course structure, including prompt refreshment breaks:

**AH: was there anything particularly you liked about the course?**

**I: She is asking if there is anything particularly you liked about this course?**

**Mandeep: ... Have tea on time, everything was done on time. I felt good and I liked it when I went there, when all of us went there. They looked after us well, all of us well... They had lots of things there to eat... Tea, fruit and about 11 o'clock at break time whatever anyone wants to eat.**

Mandeep evidently felt that the tutors cared for attendees' well-being, and appreciated this, apparently understanding that this care was exemplified by the selection of food available. The punctuality of the tea-break is noteworthy, as it suggests that the timed delivery of Course components was achieved.

### **Cultural competence**

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In addition to the structure of the course, facets of its precise delivery that had been tailored for Punjabi attendees also drew comment from these participants. The language of Course delivery, raised in all three previous Studies, also emerged:

**Varinder: It was nice, we understood, it was in Punjabi... We were happy because they were explaining in our mother tongue.... were happy**

**I: That is why they were happy, you know, to attend that course because it was in their own language**

It is evident that Varinder was pleased with the Punjabi-language delivery of the EPP, which had allowed her to understand the content, and, interpretatively, may have potentially encouraged her attendance on the Course. Additionally, as the following shows, the tutors had provided attendees with explanations of the medical terms included in the Course, which had further enhanced her understanding:

**AH: Ya, were the medical terms ok?**

**I: She is saying that medical terms, were you able to understand?**

**Varinder: Yes... I was able to understand**

**I: Ya, she is**

**Varinder: Both the ladies were very nice... Yes they were explaining in Punjabi**

**I: You were able to understand**

**Varinder: Yes**

***I: Yes, they used to translate the medical terms in Punjabi, so they could understand better***

These quotes confirm the Study IIIa finding that the availability of Punjabi-language delivery was a critical for certain participants, and the Study I finding that White tutors identified language as a potential barrier to some attendees. Implicit in this example, however, is that the medical terminology may have been too advanced (even in Punjabi), so the tutors provided additional explanations, thus ensuring that attendees comprehended the medical content. This, in turn, raises the concern raised in the previous chapter about the Biopsychosocial assumptions of the Course potentially representing a barrier to those Punjabi Sikh attendees who held culturally-specific health beliefs about their LTHC, or had low health literacy. However, Varinder's understanding of the Punjabi explanations of medical terminology on the Course, is particularly reassuring, and somewhat negates this concern. It was this participant who, in Study IIIa, understood her arthritis to be associated with internal boils and veins and who had taken *neem* tea, in order to help with her pain. However, Varinder's traditional health beliefs, which had appeared to be inconsistent with the assumptions of EPP, do not appear to have interfered with her ability to engage with the Course's content. Speculatively, this may suggest that the participant has a parallel understanding of her health and its management, from both Indian and Western perspectives.

The two quotes above, highlight not only the absolute necessity of the appropriate language of course delivery, but also the importance of identifying the appropriate use of terminology in that language, for its intended audience, identified by Study II's South Asian tutors. These quotes underscore the pivotal role of the tutors in successfully guiding attendees' through these features.



Whilst the exercise component of EPP could be clearly be defined as a *Design Concept*, the importance of one aspect of this is included here for its apparent *Cultural Competence*. Parmjeet described, in detail, how the exercise element of EPP, in which she learned more about the importance of taking regular exercise, was her favourite part of EPP, and which she was putting practice:

**Parmjeet:** The best part was that you need to go for a walk more often and do exercise and it was about for your health.

**I:** That means that part about exercise and healthy eating\* and about your health you liked the most, is that what you are saying?

**Parmjeet:** Yes, that is what I am trying to say

**I:** You know that part where they explained about healthy eating\* and exercise and all ?

**AH:** Uhhu

**I:** That part of the course was the best.

**AH:-** I see, was that new information for you?

**I:** She is saying that was this information new for you?

**Parmjeet –** I was already aware of it but it was explained. When you hear from someone you understand more and remember more.

**I:** She is saying that it was not new, you know healthy eating\* exercises because she attended the course she got bit more information in detail.., she knew the benefits.... of healthy eating\*, ya.

**R –** What about the exercises, what exercises do you manage to do?

**I:** She is saying about managing exercises?

**Parmjeet –** I do it in the morning... when I get up, I do it in the morning before I take my bath

**I:** She does morning exercises you know before having bath

**Parmjeet -** I then go outside for a walk

**I:** Then she goes out for a walk as well

**AH:** Ok, Were those things you were doing before the course or was that new?

**I:** She is saying, were you doing those things before, like going for a walk and exercise, was that new or you were doing it before?

**Parmjeet –** I was doing it before but I am doing it even more now...

**I: She is saying that it was not new, first she used to do it but since she has attended the course she is doing it more. You can say that she has increased the time like, you know she was doing less before and now she has increased.**

**AH: Has going on to the course, did it change the way you think about yourself, particularly your arthritis?**

**I: She is saying that after the course did it change the way you think particularly about the arthritis?**

**Parmjeet – (Silence) ... Arthritis is better if you carry on doing exercises, when you do not do exercises then it is worse and this hurts and that hurts\*\*. If you carry on doing then it is better.**

*\*Validator's comment: Participant previously uses the term "eating" [not here]*

*\*\*Validator's comment: Participant then adds "then you can't get up"*

Like Mandeep in an earlier quote, this indicates that walking as the exercise component of the Course was suitable for these Punjabi Sikh attendees. Parmjeet's existing awareness of exercise for health was consolidated, confirming the important contribution that improving knowledge and understanding can have upon behaviour change in disease management. This participant's auditory learning style is also noteworthy, suggesting that this was more beneficial to Parmjeet than the written materials that would have complemented this section of course delivery. Parmjeet's final comment in this extract demonstrates that she evidently understood the causal relationship between inactivity, pain management and impairment. Many Study IIIa participants were already using yoga as a self-management technique; this follow-up provides further evidence that the common stereotype that Asian women do not exercise, is flawed.

Another participant identified an example of cultural tailoring that had helped her engagement with this part of its content:

**Mandeep: They were saying to eat more fruit and eat... less fried food.**

**I: Was it about your food?**

**Mandeep: Yes it was, it was about Asian food**

***I: Uhhu, She is saying that it was about Indian or Asian food, they that they should not have much fried food and have snacks on fruit you know***

Mandeep had understood the specific healthy eating message - that had been tailored for Asian attendees. This is indicative that the appropriate language of delivery, the level of Punjabi, and the content of the food and nutrition section, had been tailored to the intended audience. The result was the successful engagement of this participant at these different levels. It was Mandeep, in the Study IIIa, who was concerned, that the diet and exercise advice that she understood was contained in EPP, would not be culturally-appropriate for Punjabi Sikh attendees; this concern appears unfounded in her own experience of the Course. It also confirms Jane's point in Study I, that food types may be an issue for ME EPP attendees that differs from White attendees. Similarly, in Study II Jangjeet was concerned that Punjabi Sikh women lacked the flexibility and empowerment to make dietary modifications: this is not evident from the quote above.

In order to identify any potential barriers to Punjabi Sikh attendees' engagement with and understanding of EPP, participants were asked whether they would change any element of the Course, what their least favourite part of it was etc. Participants offered no criticisms, and, indeed, praised EPP; the potentially flawed nature of this line of questioning is discussed later in this Chapter. The following quote was typical of all four participants' responses when asked about word-of-mouth recommendations. Based on her experiences of EPP, Parmjeet would evidently recommend it to her friends, promoting a positive overall impression of it to them, and reflecting her understanding of the Course as 'good':

***AH: Would you recommend Expert Patient Programme to a friend?***

***I: She is saying that Expert Patient Programme course you have done, would you recommend it to a friend?***

***Parmjeet: Yes, I would go and recommend to my friends that you should go and do it.Ya.***

***I: So, she would tell them that this is a good course and you should go and do this.***

**Parmjeet: When it will start, then I would tell my friends to go and do this course there.**

***I: Ya, she is going to tell them they are running the course and the venue is this.***

**Parmjeet: It is a good course and you should do it.**

Yet participants were unlikely to disagree with this leading question, which may have resulted in socially desirable answering. However, as Parmjeet expanded upon her answer without prompting, this response probably genuinely indicates her intention to pass on word-of-mouth recommendations for her friends to undertake EPP. It appears unlikely that Parmjeet would do this, had she experienced any substantial difficulty with it, particularly given her pro-social inclination, highlighted in the previous section. Thus the convenience of the EPP's venue, aspects of its inherent design and specifics of its tailored delivery appear to have converged to create a good impression of EPP for Parmjeet.

## **Summary**

Combinations of psychosocial factors influenced attendees' decision to attend EPP. Inherent features of the course's design were noted upon by participants, and attempts at tailoring were also well-received. These findings suggest that EPP may be appropriate for use with Punjabi Sikh groups.

## **Theme summary**

These Punjabi Sikh women were encouraged to attend EPP by its convenient location and timing, its free nature and curiosity about its potential benefits. Once there, participants were encouraged to engage with the Course, reassured by the confidentiality of the group setting, and benefitting from social comparisons with other attendees, and appreciative of the Punjabi-language delivery. The Action Planning, exercise and tailored nutrition elements of EPP

were understood, with the structured design apparently acceptable to participants. No barriers to EPP were identified.

#### 7.4.2 Post-EPP self-management experiences

**Table 7.3: 2<sup>nd</sup> Major Theme and Subthemes arising from Study IIIb analysis**

<b>Major theme</b>	<b>Subthemes</b>
<b><i>Punjabi Sikh Post-EPP self-management experiences</i></b>	<i>Physical</i>
	<i>Psychological</i>

In addition to recalling their experiences during the Course, participants also reflected upon changes they had made to the ways in which they managed their arthritis, and the perceived benefits that these changes had brought, following their attendance on the EPP. These are broadly grouped into the two subthemes of Behavioural/Physical Self-management and Psychological self-management.

#### **Physical changes**

Participants identified a number of behavioural changes that they had made since attending EPP, which they understood to have had beneficial physical effects. The following excerpt demonstrates how learning about the importance of exercise, had enhanced this participant's pre-existing exercise behaviour, with noticeable improvements:

**I: She is saying that after attending the course has your health gone better or has not made any difference or it has gone worse than before?**

**Varinder: No, my leg now is better than before... exercise**

**I: So does that mean it has made a difference?**

**Varinder: Yes**

***I: She is saying that she has improved, first she had pain in her legs and now with exercise and walking it has gone better than before...***

***AH: You will still do little bit?***

***I: She will do little bit?***

***Varinder – When my leg hurts more, then I do ...it and I do my work sitting on a chair***

***I – You know when it is really bad, some days it is bad, she will sit down on a chair and exercise sitting down on a chair***

***Varinder: Yes, I was doing it little bit and when you watch then you find out that this is beneficial therefore one should do it.***

***I: She used to do it before as well, but after attending the course she learnt that exercise is good for health***

Varinder clearly attributed the post-EPP improvement in her leg to the additional exercise that she was now performing. Indeed, Varinder had even adapted her exercise by performing it seated, when pain prevented its normal performance. This shows a positive self-reported physical health outcome resulting from this participant's EPP attendance. In the previous Study, Varinder described the impact of arthritis on her quality of life in terms of fatigue and stiffness, and indicated that her medication was ineffective, merely suppressing her pain, whilst tailored yoga exercises improved her ability to walk. It therefore seems plausible that she was receptive to the exercise element of the Course as it fitted her existing health beliefs and behaviours.

Parmjeet was also exercising more since EPP, she, and her arthritis pain had receded:

***AH: So has that really make much difference then to the arthritis?***

***I: Has the course made any difference to the arthritis?***

***Parmjeet: It is ...like better now, the pain is still there but it is less.***

***I: She is saying that you have attended the course and you had arthritis before and have you learnt anything new which had made difference to your arthritis?***

***Parmjeet: It made difference, It was discussed that if you do movement it will make difference. I learnt I should not carry on sitting lazy and keep thinking I am not well, I am not well.***

**I: Ya, it made difference. There was improvement than before. They also said that if you got arthritis pain you know, rather than sitting at home, she said, if you are at home and you are lazy and all that, so that helped and she knows now that if she has aches and pain to do physical exercise... rather than sitting at home.**

**Parmjeet: When there is pain, you carry on moaning and it is better to move around.**

**I: They said in the course\* that if you have arthritis pain rather than sitting at home and moaning about it, it is better to move around you know, get your body physically fit. That is what she is saying that she does that rather than you know moaning about the pain. She does physical exercise.**

**Validator's comment:** Participant does not mention this - this is interpreter's own addition

Parmjeet's experience of reduced pain since her attendance on the Course is encouraging, although she may have hoped for its elimination. Evidently Parmjeet had learned that keeping mobile helped, rather than resigning herself to the pain and fatigue, or focussing upon these unpleasant arthritis symptoms. This represents an important finding at a number of levels. Study IIIa participants reported pain as a significant feature of their arthritis experiences, and one woman had searched for advice about pain; the current phase has already identified participants' describing the exercise aspect of the Course as their favourite component (presented earlier), and now demonstrates that this behavioural change was effected.

However, Varinder, whilst also evidently understanding the exercise component of EPP, had been forced to do less exercise than she wanted, because of her leg pain:

**R: Are you still managing to do walking and everything?**

**I: She is saying that you are still managing to do walking and everything**

**Varinder: I walk little because of my leg pain,**

**I: Do you manage?**

**Varinder: Yes, little bit because of leg**

***I: Yes, she manages because she has pain in her leg you know. She walks little bit.***

***R: hmm hmm***

***Varinder: I walk outside in garden***

***I: in her garden you know***

***R: I see***

***I: she walks***

***Varinder: Ya***

***R: Does that help?***

***I: Does that help when you walk?***

***Varinder: When I get tired sitting at home then I walk little bit?***

***I: She is saying that sitting at home gives her tiredness when she goes out for a walk it does help.***

It is apparent from this quote that whilst her pain represented a barrier to Varinder taking exercise, the individually tailored walking that she undertook when she was able to, did help to reduce the fatigue she experienced. Thus, Varinder causally attributed the fatigue-reduction to her walking, the importance of which she learned on EPP. It was Varinder, in the previous chapter, whose ill-health often precluded her from attending Temple, so adapted her religious practices at home. It seems possible that her existing flexible approach to self-managing her life around her arthritis was further enhanced by EPP. As other Study IIIa participants also reported fatigue as a significant symptom of their arthritis, it appears that this may represent a useful self-management technique amongst these Punjabi Sikh women. These quotes provide encouraging evidence that walking is an acceptable form of exercise that these Punjabi Sikh women are motivated to perform, reporting reduced fatigue from this.

Another participant had revised her cooking methods since attending EPP, now avoiding fried and frozen food, in favour of boiled or baked alternatives:



**AH: Have you managed to cut down on the fried food that you eat?**

**I: She is saying that have you managed to cut down on the fried food?**

**Mandeep: Yes, I have cut down little bit**

**I: Yes, she has cut down**

**AH: So what do you do instead of frying food?**

**I: She is saying that what do you eat instead of fried food?**

**Mandeep: I boil it instead...uh... and frozen food... eat it less, and put food in oven and then eat it**

**I: She is saying that she has started to have more steamed\* and boil vegetables\* and she does not have more frozen food, instead she has more fresh veg you know. She puts the stuff in the oven as well than frying.**

**AH: Right. Have you felt any better for doing it?**

**I: Yes, she is saying that have you felt any better by taking less fried food?**

**Mandeep: Yes, better... yes**

**\*Validator's comment:** Participant does not mention steaming or vegetables

However, my leading question could have inadvertently encouraged a socially desirable response from Mandeep, both about her food preparation methods, and perceived health improvements. Yet Mandeep had evidently understood the key message of this section of the Course, recalling it 4-5 months after completion of the EPP. This extract serves to address Jangjeet's concern in Study II that Punjabi Sikh women were unable to alter their traditional food preparation methods, although it is acknowledged that this single report of dietary modification does not signify that all Punjabi Sikh women are so empowered.

### **Psychological changes**

In addition to experiencing physical improvements in symptoms as a result of behavioural change following EPP, participants described combinations of physical and psychological self-management behaviours that improved their

psychological wellbeing. For instance, one participant had learned the importance both of seeking social contact for peer-support, and of exercise, in order to help manage the isolation that she experienced, combining these into one activity:

**AH: Ok, are there any self management techniques that you learnt?**

**I: She is saying that if there are any self management techniques that you have learnt?**

**Parmjeet: It was discussed that this is what you should do if you are sad\* then go to your friends, or go for a walk... (laughs) I go to the shops.**

**I: She is saying that ...when she attended the Course ... They talked about what you say, stress management\*\*, when you are stressed or depressed\*\*\*, rather than sitting at home, go out, meet you know, friends. Talk\*\*\*\* to friends that is the new things she learnt ...and rather than sitting at home you should go out for a walk, you know.**

**AH: Do you think these things have helped you?**

**I: Do you think all these things helped you?**

**Parmjeet: Ya, it helps**

**I: Yes, she is saying, yes it helped a lot.**

\* **Validator's comment:** Rather than using the term "sad" the participant uses the term "lonely"

\*\* **Validator's comment:** Participant doesn't use the term "stress management", this is added by the interpreter

\*\*\* **Validator's comment:** Both terms; "stressed" and "depressed" are included by the interpreter- the participant actually uses the term "lonely"

\*\*\*\* **Validator's comment:** Participant uses the term "meet" rather than "talk"

Parmjeet evidently understood the link between feeling sad and the positive roles that exercise, and social support from her friends, could have on mitigating the psychological effects of isolation, caused by her LTHC. It appears likely that the behaviour of leaving the house, rather than the retail therapy, is what effected the psychological benefit that Parmjeet reported. In Study IIIa, Parmjeet expressed the opinion that the social support afforded by other attendees was more important than the identity of the tutor delivering

EPP and that the group format may be useful to boost her knowledge by learning from others' experiences. Thus it appears that this participant had a strong intuitive sense of the important role that social support played in her well-being, and so was particularly receptive to this message, which confirmed her own beliefs. The interpreter's additions were not analysed.

In the quote below, Nirmal described the psychological and physical improvement she noticed since adopting the Pacing and Action Planning techniques that she learnt:

***Nirmal: Aaayyy, I learned to plan things, don't rush things and – look on the bright side! Make plans – little bit a time! ...Not like before, when if I started it, I had to finish it. Just do what you can, then sit down and rest. Then do it again! So planning it.***

***AH: And are you managing to do some of that?***

***Nirmal: Yes!***

***AH: Has it helped?***

***Nirmal: Yes it has: since then I haven't felt disappointed 'Oh I can't do it' now. I know that I can leave it, then come back when I feel like it, then do it and leave it, so. Yes, I used to feel 'Oh I can't do, forget it, can't do it now, forget it'. Now I don't feel that way!***

Nirmal had understood that preparation to undertake tasks at a manageable pace, then resting and restarting as necessary, was preferential to her previous behaviour-pattern of dogged task completion, symptom exacerbation and resignation. She mentions Positive Self-talk, an element of EPP, without going into detail, which suggests that this was also inherently appropriate to Nirmal. This experiential example also illustrates a response shift: by accepting her arthritis symptoms, but changing her attitude towards them, extending compassion towards herself, and giving herself 'permission' to rest as necessary, Nirmal had improved physical and psychological outcomes. Thus, EPP had helped her to recognize the limitations of her illness and equipped her with skills to better deal with these, replacing negative resignation with positive acceptance.

### **Subtheme summary**

Participants reported psychological benefits that had occurred as a result of their EPP attendance. One woman was now actively seeking social support whilst another had learned to pace her daily activities to avoid frustration and negative emotional responses to her arthritis.

### **Theme summary**

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The theme of '*Post-EPP self-management experiences*' identified the positive changes that participants considered have occurred as a result of behavioural changes effected following their EPP attendance. These suggest that elements of the Course's design and concept are applicable amongst this group of Punjabi Sikh women. No barriers to these women's performance of the new self-management techniques were identified.

## **7.5 Discussion**

Study IIIb has described Punjabi Sikh women's experiences of attending a Punjabi-language EPP course, and their subsequent experiences of living with OA. It identified what encouraged them to attend, and elements of the course's generic design that appeared to be appropriate amongst this group. Similarly, facets of its tailoring that seem to have contributed to these women's engagement with it were revealed; no barriers were identified. Following their Punjabi-EPP attendance, these Punjabi Sikh women understood they had gained psychological and physical benefits from the Course.

### **7.5.1 Discussion of Results**

The first subtheme within the major theme, *Punjabi Sikh EPP Attendance Experiences*, identified combinations of both external (e.g. convenience) and internal (i.e. psychosocial – e.g. curiosity) factors that led to these women's

attendance. The success of recruiting attendees onto the Punjabi-language EPP using a personal contact, is encouraging. Chapple (2001) found this technique to be beneficial when recruiting South Asian women onto a health education intervention. The Course's timing and the accessibility of EPP's venue were clearly decisive factors for these participants. This confirms other local research that found Indian Sikhs and Hindus considered their lack of transport to be their main barrier to get to EPP (Turner et al., 2007). A substantial body of international evidence has identified the importance of the convenience of self-management courses amongst mainstream attendees, for example with White cardiovascular patients (Barlow et al. 2009), and in Kennedy et al.'s (2007) national RCT; self-management attendees in the UK and US dropped out when faced with transportation barriers (Barlow Williams and Wright, 1999; Jerant et al., 2005). The accessibility of the Course venue is perhaps of more significance to EPP attendees with arthritis, some of whom, arguably, may experience greater mobility issues than attendees with other LTHCs. Another participant attended the Course to satisfy her curiosity about how EPP may be of benefit to her. This reflects other work that suggested attendance was motivated by the need to reinforce and strengthen existing coping skills (Barlow et al., 2009; Rogers et al., 2006).

Another participant raised the free nature of the course. This is a noteworthy finding, as it has been suggested that attendees should make a nominal financial contribution toward the cost of the EPP Manual. As the Manual is still only available in English, this raises the implausible scenario of attendees on a Punjabi-language Course being charged for materials in an inaccessible format. Furthermore, given that social determinants of health inequalities, including poverty, low educational status and ethnicity are related (WHO 2005; CSDH, 2008), it appears that payment for health interventions such as the EPP may exacerbate existing inequalities, by deterring potential attendees from this group. Further research with majority and minority participants, about the perceptions of payment for health education appears necessary. Thus, the current phase of this Study suggests that invitation to attend by a known

community member, careful consideration as to the Course's timing and venue's accessibility, in addition to the provision of information about how attendees may benefit from EPP, may represent a successful recruitment strategy amongst this population.

Several of the inherent *Design Concepts* of EPP appeared to be well-received by these participants. For example, the confidential nature of the group discussions assured one participant's participation. Given that Asian families are amongst the most "...closed and private of all social groups" (Bhopal, 1995; pg.156), confidentiality may be particularly important to South Asian EPP attendees. One report of this cannot be generalised; however this finding may be worth pursuing in subsequent research, to establish whether potential Punjabi Sikh attendees are being deterred by concerns about disclosing personal information to other community-members. This is particularly important given that EPP is often marketed as an opportunity to share experiences; confidentiality could therefore appear as part of a recruitment strategy, too.

The benefits of group self-management are well-reported in the literature, and its social comparison component is widely recognised amongst White attendees (e.g. Barlow, Bancroft and Turner, 2005; Barlow Edwards, Turner 2009; Barlow et al., 2009; Barlow, Williams, Wright, 1999, Kennedy et al., 2007). For example:

(Barlow,  
Cullen and Rowe; 2002)

Similarly, Yalom (2005) recognised that the strengths of therapeutic group interventions include the elements of sharing, group bonding and universality of experience; South Asian people were not specifically considered. One

participant's recognition that her condition was less debilitating than she had previously recognised, represents a positive response shift (Osborne et al., 2006), which has not apparently been reported in South Asian people before. Study IIIb therefore offers tentative confirmation that such previous reports of the multi-faceted benefits of group interventions, typically comprising White participants, may apply in this ME sub-group. This is believed to be the first time such findings have been reported by Punjabi Sikh EPP attendees. Clearly, extensive research is warranted to investigate this in detail.

Similarly, Action Planning proved useful for participants in the present Study; this confirms research with White participants (e.g. Barlow Turner Edwards, 2009). This finding does not bear out concerns raised in Study II about older, non-English-speakers not understanding the concept of goal-setting. Indeed, participants in the present Study derived evident pleasure from sharing their successfully achieved goals with other group-members. In turn, this may represent preliminary evidence that the concepts of skills mastery and self-efficacy (Bandura, 1977; 1997) are psychological constructs that have practical applications for Punjabi Sikh people. Clearly, more detailed studies, considering these specific psychological variables that are central to EPP, would be required to determine this amongst Punjabi Sikh people. Participants' engagement with the 'walking for exercise' message of EPP is also noteworthy, and I discuss this in detail with reference to the second theme.

The language of the EPP's delivery was raised in all the previous studies within this thesis. Study IIIb found that Punjabi-language delivery did assist with attendees' abilities to comprehend the Course's content, contributing to its Cultural Competence. The current research therefore adds to weight to Szczepura, Johnson et al. (2005)'s suggestion that the linguistic tailoring of health resources is a prerequisite to cultural competence. However, the medical terminology required explanation in accessible lay terms. This suggests that the extensive 'teething problems', reported by South Asian tutors in

Chapter Four, still need to be addressed, and confirms Walker et al.'s (2005) findings that health literacy may represent a barrier to some ME attendees, including, in the present study, Punjabi Sikh women. This finding confirms Szczepura, Johnson et al. (2005)'s assertion that health education materials require developing and testing for specific cultural, ethnic and linguistic groups. Equally it gives credence to the development of a culturally competent EPP to be designed in association with Punjabi Sikh community-members, which can address any tensions between the Biopsychosocial assumptions of EPP, and participants' culturally-situated health beliefs. Thus, these findings further support assertions arising from Study II and IIIa that tailoring EPP to accommodate attendees with low levels of health literacy would be beneficial.

The content of the food and nutrition section of the Course had been culturally tailored, which appeared to further participants' engagement: references to Asian foods were clearly appreciated and contributed to Ps' understandings in this sample. This apparently culturally competent improvement in one component of the Course, confirms that CC 'is a developmental process that evolves over an extended period' (Szczepura, Johnson et al., 2005). These findings collectively reinforce the need for meaningful engagement with target communities, which had not occurred in the development of the formative Punjabi EPP, reported in Study II. I consider the participants' perceptions around walking behaviours in the next theme's discussion.

The second major theme, *Post-EPP Self-Management experiences*, described participants' physical and psychological self-management behaviours. All four participants reported behavioural and/or psychological improvements as a result of their EPP attendance. Several participants described how taking more, however limited, exercise had improved pain or fatigue. This confirms previous research by Walker et al. (2005) with non-English speakers, which identified that exercise was recognised as necessary to self-manage arthritis. The present findings further contribute a cross-cultural dimension to existing studies that



have identified behavioural changes, including exercise performance, amongst participants four months following attendance at a self-management course (e.g. Barlow, Williams, Wright, 1999; Barlow, Turner, Wright, 2000). As South Asian musculoskeletal patients in Study IIIa and elsewhere report high levels and widespread pain (Allison et al., 2002; Macfarlane et al., 2005), EPP's success in pain-management in the current sample is notable. If this finding is repeated with similar groups elsewhere, this benefit may also prove to be a useful marketing tool.

This follow-up Study has revealed that walking for exercise is an inherently acceptable self-management technique amongst this Punjabi Sikh group; participants' engagement with it as part of their Action Planning whilst on the course now appeared to be ongoing. Given that participants understood the relationships between physical activity and both pain- and fatigue-management, and that South Asian people report more severe and more widespread pain than other groups, this is a potentially important finding. This may have scope for health interventions beyond the present Study, if found to be acceptable to the wider Punjabi Sikh community; further research again appears warranted. It is notable that prior to their EPP attendance, no Study IIIa participant had intimated that improving her fitness was a concern; highlighting this benefit may prove to be another facet of successful Punjabi Sikh recruitment. In their systematic review of 48 walking-promotion interventions, none of the studies Ogilvie et al. (2007) identified were aimed specifically at ME groups. The authors acknowledge that targeted walking interventions "*may be preferentially taken up by better-off groups in the population and may therefore have the potential to increase health inequalities*". This again underscores the need for any such future intervention to be developed in close association with its target population; those that have done this, are primarily with African Americans (e.g. Brownson et al., 2004; Keller et al., 2004; Dunton and Robertson, 2008). Collectively, the data presented here offer preliminary evidence that the common misconception that South Asian women do not exercise is unfounded amongst these Punjabi Sikh women.

One participant perceived that she had benefitted from reducing her dietary fat intake. This confirms previous research by Walker et al. (2005) with non-English speakers, which identified the importance of dietary control as a self-management technique. The present findings further contribute a cross-cultural dimension to existing studies that have identified behavioural changes, including in 'dietary habit' amongst participants four months following attendance at a self-management course (e.g. Barlow, Williams, Wright, 1999; Barlow, Turner, Wright, 2000).

Participants also reported psychological improvements following their EPP attendance, having practiced self-management techniques they learned. Improved peer-support through increased social contact had reduced one woman's sense of loneliness, demonstrating a psycho-social benefit resulting from her attendance. This supports evidence from Focus groups with Gujarati Hindus and Punjabi Sikhs, which identified that social isolation was a significant feature of their arthritis (Turner et al., 2007). It also confirms Walker et al.'s (2005) finding that overcoming social isolation was important to some ME participants with LTHCs. Thus the current findings confirm the importance of addressing social isolation in individuals from a group who are often perceived as 'collectivist' and self-supporting.

Pacing, reported in other disease populations to be a valuable fatigue-reduction strategy (Barlow Turner Edwards, 2009), had improved one participant's psychological outcome. These emotional improvements may offer some support for Swerissen et al.'s (2006) RCT of SMP in non-English-speaking migrants in Australia, who had significantly better outcomes on health distress (and others) following attendance on linguistically-tailored courses. The present exploration also provides an early indication that EPP may afford some short-term improvements in these Punjabi Sikh participants' self-efficacy and health perceptions, with reduced pain and fatigue reported (for one participant respectively), confirming Foster et al.'s (2005) Cochrane review with

predominantly White populations. Thus, this preliminary evidence suggests that Punjabi Sikh attendees may also reap similar short-term psychological benefits from adult educational interventions, as their White counterparts. Clearly, this important finding warrants detailed investigation amongst Punjabi Sikh populations.

In many of the quotations presented above, I had asked participants whether they felt differently about themselves and their arthritis since attending EPP. This was an attempt to identify psychological changes such as response shift (e.g. enhanced self-efficacy, reduced frustration, better illness acceptance etc. (Osborne et al., 2006), that might have occurred since their EPP attendance. Yet It is a highly noteworthy observation that most responded *not* about their personal feelings, but about their preferred elements of the Course. This raises interesting questions as to whether the concept of self-reflection translates well, or if this may exist as a more Western construct. It appears unlikely that it is impolite to discuss such personal matters publicly, given the positive responses that participants gave regarding the group structure, and other findings presented here. As the interpreter in Study IIIa suggested that these women may never have been asked about themselves before, this may simply reflect that they did not know how to answer this question.

Importantly, no barriers to self-management education, engagement and understanding, were identified, nor anything that prevented these Punjabi Sikh women from performing new techniques after their EPP attendance (I have discussed the suggestion that tailoring around health literacy could be better addressed). I consider the potential for selection bias shortly. When asked to propose improvements that could be made to the Course, participants presented a positive overview of their experiences of the EPP, and all attended each session. This supports other qualitative research which reports positive attendance experiences, amongst mostly White participants (e.g. Barlow Williams and Wright, 1999), and in ME groups (Swerissen et al., 2006). The

potentially flawed nature of questioning Punjabi Sikh participants about shortcomings of the Course is discussed in the next section.

Encouragingly, all participants in Study IIIb would recommend the Course to friends, which, given the importance of social communication networks in South Asian communities (Randhawa, 2005), may contribute to boosting attendance by Punjabi Sikh community-members. Had any Study IIIb participant dropped out of the Course, their perceptions of the EPP may have proved insightful; all four completed the Course. Barriers to *attendance* (rather than engagement with and comprehension of content) may have been elucidated from the six Study IIIa non-attenders, although such interviews in White population rarely reveal reasons beyond those given during tutors' routine follow-up enquiries.

### 7.5.2 Limitations

A number of limitations of Study IIIb need to be addressed. Firstly, the invitation to attend EPP by the BME Lead represents a departure from self-selection – the normal EPP recruitment strategy. Thus, participants' decision to attend, which may be considered to be the first step towards becoming a more successful self-manager (Wright et al., 2003), required little deliberation about the considerable effort and commitment that psycho-educational interventions demand from participants (Barlow, 2002). Furthermore, this may have resulted in participants in Study IIIb being less motivated to adopt the self-management techniques included on EPP. Thus, the profile of the present participants may differ from those in other qualitative studies - not just in terms of their ethnicity; clearly this may have influenced their perceptions that are reported here. However, given that all four participants attended every week of the Course, this method of recruitment did not have a detrimental effect on attrition.

It is highly noteworthy that local anecdotal evidence suggests that it is socially unacceptable in Punjabi Sikh culture to complain about or criticize something

that is offered free of charge, or with good intention. It therefore appears plausible that my efforts to identify areas where EPP could be improved, may itself suffer from an inherent lack of cultural competence with this participant group. Prior to conducting the interviews, attempts to avoid such a cultural *faux pas* were undertaken by asking the Punjabi Sikh interpreter to check the interview schedule; this issue was not identified. Time constraints and a highly limited participant sample precluded conducting a pilot of the interviews, exacerbating this oversight. Thus, the absence of suggestions for improvements to the Punjabi-language EPP's content or delivery mode cannot be assumed to indicate that no improvements are necessary to further enhance it. Indeed, given the interpreter's observation that participants' Punjabi-language skills were not advanced, this may simply reflect their inability to articulate any concerns that they had identified. The reported Findings should therefore be interpreted with caution. Further work to determine how best to elicit this vital feedback about the Punjabi EPP is warranted. However, revealing such cultural insights about inappropriate lines of questioning may itself serve a useful purpose in subsequent research, and therefore itself represent a valuable observation. The extent to which the Findings can be attributed entirely to participants' cultural background is also unclear: they live in an area of urban deprivation, so it is likely that their experiences and understandings are also coloured by poverty. The relative extent to which the inter-related factors of poverty and ethnicity will have influenced these data is impossible to determine.

Similarly, another threat to the validity of these findings is that a selection bias in the participants may have occurred. As only those participants who had attended EPP were sampled, the views of people who chose not to attend, are not represented here. Future research should consider interviewing those who did not accept an invitation to attend EPP, in order to identify further attendance barriers, and so address this oversight in the Study III's design; however as previously stated, this rarely produces in depth data amongst White non-attenders. Additionally, participants may have displayed an optimistic

response bias, in that they reported positively about EPP as they did not want to admit that they had chosen to do something that they did not enjoy. Furthermore, the interview questions about the EPP itself, and participants' subsequent self-management practices, were retrospective in nature and thus may not accurately reflect reality (Barlow, Cullen and Rowe, 2000). However, this study's aims and methods are broadly in line with other EPP 'completer' studies. Similarly, the extent to which these findings are attributable to the Punjabi Sikh women's ethnicity cannot be determined: their previous life experiences around gender, poverty etc. will have contributed to their accounts. The methodologically necessary homogeneity of Punjabi Sikh Indian women participants with arthritis evidently excluded Punjabi Sikh men, those with other LTHCs, and from other South Asian ethnicities; further research should target such groups. Finally, the need for longer-term follow-up is acknowledged; whilst 3-6 month post-EPP interviews are the norm, it would be of interest to establish whether the reported benefits are maintained, for example, after 12, 24 months, or longer amongst ME groups.

Methodological considerations around the central importance of the roles of interpreters and translators were detailed in Chapter Three, and I examine the issues raised in detail in Chapter 8.2.2. I again acknowledge that differences in meanings of concepts may have compromised the linguistic equivalence of the translated data on which my analysis in the present Study was based. However, the present Findings provide evidence that IPA studies involving interpreters and translators are warranted if the gains from speaking to a particular group outweigh the costs from not speaking the same language, (Smith, 2004).

As detailed description and interpretation of participants' rich accounts is the aim of IPA research, it should be noted that the results of this exploratory study cannot be generalised to other Punjabi Sikh women. Similarly, I again accept

the Findings represent my own interpretations of the data; alternatives may exist.

### 7.5.3 Strengths

This study also has a number of strengths. It is believed to be the first academic study of Punjabi Sikh experiences of attending a Punjabi-language EPP, and is therefore considered to be original. As such, every subtheme contained in the Findings represents a novel contribution to knowledge about this group's EPP experiences and their post-EPP self-management experiences. These preliminary data may therefore stimulate interest in this under-researched area, and serve as useful starting points for future research, as highlighted throughout. The qualitative method of enquiry adapted for this study has given unique insights into these participants' experiences, permitting detailed understanding from the Punjabi Sikh women's perspectives. The use of IPA on translated data in Study III is also believed to be a methodological innovation, and the painstaking approach to validation adds to the Study's methodological rigour. Again, this may elicit debate as to how best to progress this field. The "time–venue-based" sampling technique use in both phases of Study III has proved an effective recruitment strategy and may be useful to other researchers in future (Crosby et al., 2009). Furthermore, the planned longitudinal design (Flowers, 2008) of Study III has allowed the comparison of participants' preconceptions of EPP with their lived experiences of it, identifying a number of ways in which a recruitment strategy may encourage Punjabi Sikh people to attend. Importantly, it has enabled the identification of self-reported physical and psychological improvements as a result of participants attending EPP, across a period of time. As this longitudinal data-collection was negotiated at the start of Study III, participants were aware of my intentions to conduct interviews following EPP. There seems little scope, therefore, for misunderstandings arising from participants wondering if they gave the 'wrong' answers within the first interview (Flowers, 2008). This 'bolder design' (Smith, 2009; p.52) represents a further strength of this study.

## 7.6 Chapter Seven Summary

This novel research has revealed that attendance on EPP by these Punjabi Sikh participants was influenced by a complex interplay of both external and internal factors, with personal contact from a known community-member representing a successful recruitment strategy. Punjabi-language delivery at an accessible venue encouraged attendance on the 'free' Course, whilst the confidentiality of structured group discussions encouraged engagement with the apparently culturally competent and conceptually acceptable content. Participants reported physical and psychological improvements 4-5 months following EPP attendance, with no barriers to self-management education identified. Notwithstanding the methodological caveats raised, the results of this small-scale, exploratory study suggest that EPP for these Punjabi Sikh women with arthritis may have improved their physical and psychological well-being.



# Chapter Eight: Discussion

## Chapter Contents

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#### 8.1 Thesis Summary

##### 8.1.1 Summary of key findings

The primary aim of this research was:

***to describe the experiences of living with a LTHC, identifying barriers to and facilitators of self-management practices, including attendance on a self-management programme, amongst people from South Asian backgrounds.***

I have achieved this as follows.

Interviews with five non-minority White EPP tutors, who had delivered an EPP Course to English-speaking South Asian attendees, revealed encouragingly positive cross-cultural delivery experiences. The tutors' sometimes dichotomous personal understandings about ethnicity-specific courses for people from South Asian backgrounds, and the perceived appropriateness of delivering EPP with interpreters, were addressed. Tutors' perceptions of South Asian attendees' needs were identified and their own perceived needs in terms of training requirements, particularly cultural competence training, were emphasised. The complexity of

delivering this psycho-educational health intervention in a multi-cultural society was confirmed.

The need for insiders' perspectives into the South Asian cultural context of EPP delivery to South Asian attendees was identified and three Punjabi Sikh EPP tutors provided this. Facilitators that may promote EPP amongst South Asian communities included faith-placed recruitment and delivery of both taster sessions and the intervention itself, may help to raise awareness of EPP in different South Asian groups. This would also remove intra- and inter-cultural tensions between attendees from diverse communities that were exposed, whilst facilitating delivery for tutors. Sensitive recruitment by gender and caste were revealed as potential facilitators to Punjabi Sikh attendance and engagement. Culturally refined, non-text-dependent innovations in course content, materials and delivery media, suitable for those with low health literacy, require development in partnership with community-members. This would address barriers that the current EPP delivery mode presents, including the 'level' of language and medical content of Punjabi-language EPP for Punjabi Sikh attendees, who the tutors perceived to have low levels of education (in any language) and poor health literacy.

It was evident that insights from Punjabi Sikh community-members would provide illuminating accounts of their culturally-situated experiences of living with a LTHC, that had not previously been considered. Additionally, potential barriers and facilitators to their EPP attendance and performance of self-management behaviours may be identified, which could inform any future cultural tailoring. Ten interviews were conducted with Punjabi Sikh Indian women with arthritis, in English, Punjabi, or in both languages, with an interpreter where necessary, in an innovative methodological adaptation of the IPA approach. Participants experienced arthritis as having detrimental physical, psychological, and social consequences on their lives. However, the women's vibrant experiential accounts showed that they were highly motivated and

empowered to effect positive changes in order to self-manage their arthritis. Participants' extensive array of self-management behaviours integrated prescription medication with traditional Indian CAM, including yoga and religious and spiritual practices, tailored to their individual needs. Psychological, physical and pragmatic obstacles to EPP were identified, with the intervention's current cultural competence meriting particular consideration. The necessity of a convenient venue with courses available in Punjabi may encourage EPP attendance amongst this group. Thus, the need was confirmed for a culturally tailored intervention to be developed with the Punjabi Sikh community, to allow self-management education that is meaningful to these attendees. Importantly, in this Punjabi Sikh sample, participants had an inherent acceptance of self-management itself.

Following on from this, four of these Punjabi Sikh participants attended a Punjabi-language EPP and were interviewed about their experiences of this, and their subsequent experiences of living with arthritis. Psychological and external factors influenced participants' EPP attendance, with personal contact from a known community-member, and Punjabi-language delivery at an accessible venue, encouraging the Punjabi Sikh women's attendance on the 'free' Course. The confidential group format allowed them to engage with the apparently culturally competent and conceptually acceptable content. However, an inappropriate line of questioning may explain the absence of suggestions for tailoring. Participants attributed physical and psychological improvements 4-5 months following EPP attendance on their enhanced understanding and performance of exercise behaviours, enriched social support and pacing activities, learned on the Course. Importantly, the South Asian tutors' perceptions, raised in Study II, that EPP was unsuitable for similar groups was not corroborated: no fundamental barriers to self-management education were identified.

Collectively, these Findings offer evidence that the concept of self-management is inherently acceptable to these Punjabi Sikh women, who were

already highly adept at self-managing their arthritis. The Punjabi-language EPP expanded these Punjabi Sikh women's existing arthritis self-management behaviours, leading to perceived improvements in physical and psychological well-being. This suggests that EPP may provide a useful template on which to base sensitively tailored courses. Data provide preliminary insights into recruitment strategies and features of such courses that could be developed in partnership with Punjabi Sikh people to overcome identified barriers and ensure its improved cultural competence. It is understood that these Findings, across all three Studies, represent novel contributions to knowledge, as this is believed to be the first academic research of its kind to investigate arthritis self-management amongst Punjabi Sikh women.

### **8.1.2 Discussion of Findings**

The above key findings will now be integrated and discussed in relation to how EPP can better meet the needs of Punjabi Sikh attendees with arthritis. I start by examining issues affecting tutors, before addressing aspects of the intervention's marketing and recruitment, then finally considering improvements that could be made to the course itself.

This Study has identified several ways in which EPP tutor training could be enhanced. Delivering multiethnic EPP courses with interpreters has interesting implications for cross-lingual delivery on such courses; however, as Rea (2004) advises, using interpreters is not always straightforward. Interpreters are crucial in effective communication between diverse populations, acting as mediators, conveying precise information, translating meaning and communicating subtle and overt dynamics. An advantage is that the interpreter and client share body language and culture (Rea, 2004). However the person using the interpreter (the tutor, in the EPP context) may feel excluded if eye contact is not maintained, or if s/he is not spoken to directly, or is ignored altogether. Walker (2005, personal communication) advised this happened during focus groups for Walker, Weeks et al. (2005). To overcome these difficulties, Rea (2004) suggested ongoing

collaboration between the same facilitator and interpreter enhances communication. Ideally, the tutor and interpreter should meet before and after every session, with the interpreter considered a co-worker; clearly this has pragmatic challenges in terms of the time, cost of paying for the interpreter's professional services, and, potentially, having the interpreter EPP-trained. At the time of the interviews, delivering EPP to attendees with an interpreter had not been widely considered; it is, now, being increasingly used as a delivery model to ensure people are not excluded from the Course on the grounds of language. As working with interpreters is something EPP tutors of all ethnicities might encounter, it seems appropriate for EPP-CiC to train all tutors how to best do this.

Some tutors' unwitting lack of competence and confidence when dealing with attendees from different ethnicities confirmed their need for cultural competence training, in line with paid health professionals (e.g. Papadopoulos et al., 2004). This is again unlikely to be an area of training that is required only by White tutors and has therefore been suggested as another component of tutors' training. Indeed, in direct response to my finding, the EPP-CiC invited an application for funding such a training intervention, which is outlined in section 8.4.2.

The complexities of cross-cultural delivery are confirmed by the findings from all Studies. White tutors did not report any specific issue that had been problematic during multi-cultural delivery. Similarly, a South Asian tutor suggested that attendees on a mixed-ethnicity English-language EPP comprehended more of the course than a South Asian group on a Punjabi course. Together, these could be taken to suggest that few issues arise during English-language EPPs, attended by people from South Asian backgrounds – yet this is unlikely to be a valid conclusion. Whilst the English-speaking South Asian EPP attendees that tutors had encountered were (speculatively) likely to have been more acculturated than attendees on Punjabi courses, their language ability alone seems unlikely to remove the issues of cultural competence raised. They may, however, have been better able to deal with such issues. Subtle intra- and inter-group differences between EPP attendees

from divergent South Asian backgrounds were highlighted, and the lack of tailoring to some attendees' particular religious and linguistic requirements was clearly highly problematic. The Punjabi Sikh community-members recognised the need for culturally competent tailoring, in addition to the availability of courses in Punjabi, confirming the need for EPP to be refined for use with specific groups, as in Griffiths et al (2005). The way in which this might be done is discussed now.

This Study has identified ways in which this intervention could be better marketed to improvement recruitment amongst Punjabi Sikh attendees. Edwards et al. (2007) noted that low participation rates are endemic across health education and promotion interventions. They suggested combinations of active and passive techniques for promoting and marketing material, and, importantly, acknowledge that success depends on characteristics of target audience. This certainly appears true in the current Study. The provision of taster sessions, to allow potential EPP attendees to make an informed choice prior to committing to the Course, may avoid some of the potential barriers that South Asian tutors identified, and that the Punjabi Sikh women revealed. For example, attendees could be made aware of the structured nature of the Course, to overcome perceptions of it as a social event, and sessions may be able to convey some basic issues to enhance health literacy. Once tailoring has taken place, elements of the Course's culturally competent delivery materials and media, in addition to refinements in content, could be highlighted to further encourage attendees. The delivery of such taster sessions, and the intervention itself, in locations that South Asian attendees are comfortable and familiar with, such as their places of worship, may assist with caste, gender and religion-specific recruitment (as appropriate), thus addressing other potential barriers that this research identified. By delivering in locations already used by South Asian groups, the convenience of the Course venue would be assured.

Importantly, this research has identified the need for well-designed, non-text-dependant Course materials and content. This may help to overcome barriers for those with low literacy (in any language, including English) that Punjabi Sikh tutors identified, and issues around health literacy raised explicitly in Study II and implicitly in Study III, as recognised by Greenhalgh et al. (2005) and Walker et al. (2005), in addition to the level of formality of the spoken Punjabi. Such innovations may be able to address apprehension around taking medication whilst acknowledging traditional Indian CAM use. Punjabi Sikh attendees' yoga practices and the acceptability of walking for exercise, may prove useful when tailoring the exercise component of the Course.

Several Punjabi Sikh community-members expressed no specific requirement for Punjabi-language courses, as their English was advanced enough to facilitate their comprehension. Whilst the standard, generic, English-language EPP is clearly not tailored for Punjabi Sikh attendees, Punjabi Sikh participants would have possibly been aware of the likelihood of this. Thus, it should be noted that even when asked to specify their requirements, some Punjabi Sikh participants were keen to fit around existing arrangements; this confirms the importance of offering choices when practicable, and close involvement with community-members.

An unequivocal finding, central to the whole thesis, was the confirmation that no fundamental barrier existed to the concept of self-management itself, amongst these Punjabi Sikh women. Participants were pro-actively self-managing their arthritis, with their religious practices and spiritual beliefs positively contributing to this, confirming previous research in other patient/religious samples (e.g. Çoruh et al., 2005; Harvey 2008; Ismail et al. 2005). The Punjabi Sikh women enjoyed the group course format, and content such as action planning, exercise behaviours, enriched social support and pacing activities. Reporting physical and psychological benefits resulting from the behavioural changes that they had effected as a result of their EPP attendance, all would recommend the Course to friends. Thus, the South Asian tutors' concerns that elderly Punjabi Sikh people

appeared to misunderstand elements of the Course's purpose and content were not substantiated by participants during the post-EPP interviews. Whilst the Punjabi Sikh women themselves were reticent to identify areas of the Course that could be further improved, this could be overcome by culturally tailoring EPP **with** the Punjabi Sikh community, not **for** them.

Collectively these findings confirm the appropriateness of self-management group education amongst this group of Punjabi Sikh women. With sensitive refinement, EPP is potentially beneficial for this population. The considerable work that is required to achieve this is outlined later in this Chapter.

## **8.2 Methodological considerations**

Moving away from the Findings, methodological considerations will now be examined. Firstly, I consider issues around the qualitative nature of the research reported in this thesis, before addressing specific concerns around the methodological approach used in the final Study.

### **8.2.1 Generic methodological considerations**

The novel, exploratory nature of all three Studies and the understanding that literacy could not be assumed amongst Punjabi Sikh community-members, required a qualitative methodology to be adopted. The aims and objectives required descriptions and interpretations of the meanings that phenomena had to the participants who had experienced them, which led to an IPA on data generated in semi-structured interviews.

IPA allowed me to explore "*participants' personal and lived experiences*" and look "*at how they make sense and meaning from those experiences*" (Smith, 2004, p. 48), whilst allowing "*deep issues to surface and make unheard voices*



*understood"* (Larkin et al., 2006). This is apparent in the present thesis, when White and South Asian tutors' gave dichotomous accounts of their experiences of delivering EPP to ME attendees, highlighting their sometimes opposing personal understandings of its complex social and cultural context. Similarly, an insider's view of the Punjabi Sikh women's worlds was revealed in the final Study, by giving meaning to the cultural and social contexts (Ong and Richardson, 2006) of their eclectic self-management behaviours, prior to and following their EPP attendance.

In terms of rigour, 22 interviews with 18 participants across the three Studies, falls within Flower's (2005) IPA review findings, which identified sample sizes ranging from 1-40. A larger sample size would have compromised the idiographic emphasis of detailed phenomenology, insightful hermeneutics, and nuanced analysis (Smith, 2008) that IPA studies exact. Given the highly nuanced analysis of participant's dynamic accounts presented in Chapters Four to Seven, such compromises appear to have been avoided. The Study's aims determined that  $N=18$  was an appropriate sample size.

Considering the transferability of the Findings, qualitative studies including the present one, may examine a specific phenomenon in a particular group, to understand the internal dynamics of that phenomenon. As the research does not aim to generalise beyond the group, it is, Willig (2001) argues, not an issue. However, if, as in this Study, the findings may have implications beyond the participants, the research may identify explanations that potentially apply to similar others (Willig, 2001). Whilst sweeping generalisations are not appropriate, comparisons with other cases within the study and reference to other comparable studies, may serve to start theory-building.

Considering the reliability of my Findings, the iterative nature of IPA analysis means that the ongoing analytic process allows themes to develop, which are

expected to change during this process (Smith 2008). The reliability of my analysis was confirmed by returning to the transcripts, to ensure that identified themes were present. This represents a strength of this work, which revealed deep issues that may not have been immediately apparent to a researcher unfamiliar with the data. The IPA analysis represents my interpretations of participants' understandings, and experiences; I explicitly acknowledge that other multiple explanations may exist. The provision of transcript excerpts to support my analysis allows the reader to determine the reliability of these Findings.

Sim and Wright (2000) asserted that the concept of validity may not apply directly to qualitative data; however, the present Study does meet the criteria for judging the validity of qualitative research (Yardley, 2000 in Langdridge). The socio-cultural context of the study has ensured my sensitivity throughout this thesis as necessary. The need for commitment, rigour, transparency and coherence involve consideration of the likely completeness of a sample, interpretative depth in data-analysis, and the coherent and plausible presentation of findings with acknowledgement of other potential interpretations. My strenuous attempts at achieving such rigour were presented in Chapters 4-7 of this thesis and are discussed in this Chapter. Smith (1999) advocated that IPA research should be judged primarily on how illuminating it is of the particular cases studied and that the 'micro-level theorising' should be richly informative of those particular individuals. Recently, Crosby et al., (2009) argued that a study's value should be judged by the practical relevance of the research question to the target population; this has evidently been achieved in the present, applied research. Finally, I have clearly met Porter's "*realist approach to validity*" (pg.79, 2007) by providing beneficial information about Punjabi Sikh self-management experiences, in the Findings of this thesis.

### **8.2.2 Methodological considerations around cross-lingual qualitative research**

Several Study III interviews were conducted entirely in Punjabi, before translation into English for my analysis, and others were conducted in a three-

way, bilingual interviews; the implications of this are considered now. The central importance of the roles of interpreters and translators were detailed in Chapter Three, and I acknowledge that differences in meanings of concepts may have compromised the linguistic equivalence of the translated data on which my analysis was based. Time and budgetary constraints precluded a full back-translation of the transcripts. However, the same person interpreted during interviews and translated Study IIIa transcripts, so she was in an excellent position to ensure that continuity of conceptual equivalence was retained as far as possible. She is a qualified NHS interpreter, and had been briefed, so minimising any such effect in this Study. However, if the Study IIIa interpreter/translator had misunderstood or mis-interpreted during the interview, this error could be carried forward into the translated transcript. To address this, transcripts were validated by another qualified NHS interpreter, who listened to the recordings whilst reading the translated transcript, noting any different opinions. At a meeting afterwards, they discussed and agreed any changes, such as the example given earlier when 'Ladies Day' was considered inadequate to convey the atmosphere of the event, so I was furnished with an explanation and the Punjabi 'satsang' was used in the transcript.

A different interpreter was necessarily employed in Study IIIb raising concerns about differences in linguistic choices from the 'dazzling array' (p.3) of possible word options (Temple and Edwards, 2002) between the two individuals. However, as each interpreter performed that entire phase's interpreting, any individual differences between the two interpreters' language-choice use should be minimised to within each phase of Study III. Pragmatic constraints again precluded a full back-translation of the transcripts in Study IIIb, so a validation technique was developed to ensure the conceptual equivalence had been maintained (Hipwell, 2009). A fluent Punjabi-speaker, KC, who is health-literate and research-trained, listened to the audio-files of the three Punjabi-English interviews, whilst reading the English translations. KC identified any potential discrepancies by annotating the English transcript using the 'track changes' feature of Microsoft Word 2007. This alerted me to any areas where I

needed to exercise caution during analysis, such as those highlighted in the Findings of Chapter Seven. For example, in one of the data extracts, KC identified that the interpreter had employed the terms 'sad/depressed/stress management' when these were not actually used by the participant. IPA was only performed on the verified sections of data, ensuring that my Findings represented the views expressed by participants themselves, and not those of the interpreter. Highlighting that discrepancies occurred is not intended as a criticism of the interviewer, who provided crucial 'live' interpretations during the interviews, without the opportunity to pause and consider alternative English interpretations for any length of time; clearly the validator was afforded this luxury. Rather, it highlights the pivotal position of the interpreters/translators and validator in the present thesis, whilst underscoring the intricacies of this type of cross-lingual research.

When determining the trustworthiness of cross-cultural interview research involving interpreters, Wallin and Ahlström (2006) advocated that a number of factors should be explicitly addressed. See Box 8.1 for the prerequisite information that they considered was necessary for this.

- Number of interpreters
- The interpreter's background (e.g. gender, ethnicity)
- Interpreting style
- Seating arrangements
- Competence (training)
- Interpreter(s) visible or invisible in the research process
- Interpreter(s) impact on the findings.

**Wallin and Ahlström (2006)**

**Box 8.1: Information required to determine the trustworthiness of cross-cultural interview research**

The present Study has not only addressed the issues raised by Wallin and Ahlström, but has attempted to present an integrated account of the efforts made to ensure trustworthy interpreting *and* translating, including validation, took place.

In another example of the complex nature of such research, during the debrief sessions following each interview in both Study IIIa and IIIb, both interpreters highlighted the women's poor linguistic skills in Punjabi, revealing that participants were unable to express themselves clearly. The Study IIIa interviewer advised me that some participants would never have been asked their opinion in their life, so simply had never considered relationships between e.g. God and illness, and lacked in-depth insight into their own beliefs, experiences and understandings. This may have contributed to a paucity of richly detailed data on which to base detailed IPA analysis. However, many of the Findings reported in Studies IIIa and IIIb represent illuminating insights into this group's experiences and understandings, so the Study does not appear to have suffered unduly as a result of 'thin' data. Limited eloquence, even in participants' primary language, is likely an inherent feature of research with people of low educational status, irrespective of their ethnicity, and was regarded as a challenge rather than an obstacle in this research (Pitchforth and van Teijlingen, 2005). Indeed, this suggests that I had accurately identified my target group of low SES South Asian women and made previously unheard voices understood (Larkin et al., 2006). It underscores the necessity for inclusive consideration in policy decisions (including EPP implementation), so needs of the most vulnerable are not overlooked.

Whilst the recruitment process attempted to give voice to the previously unheard group of South Asian women in an area of urban deprivation in Coventry, in so doing, the most vulnerable may have been overlooked. Those who were unable to attend the social-group, such as the house-bound, may have held very different understandings about the phenomena investigated in

this thesis. However, a balance between inclusivity and pragmatic necessity has produced the rich and varied, sometimes contradictory data, presented here. Another drawback of the recruitment strategy used is that participants self-selected for interview, and may have different characteristics from those who chose not to come forward. Finally, I must acknowledge that it is impossible to discern the extent to which Study III's Findings are a result of participants' ethnicity, and the extent to which other influential factors in their lives, such as their gender or socio-economic status, contributed to their responses.

Conducting IPA on translated interview data is believed to be a methodological innovation and therefore represents a strength of this thesis; however, it raises a number of issues that will be addressed now. As previously discussed, a pragmatic methodological approach must be adopted to address a study's aims. This thesis is evidence supporting Smith's (2004) acknowledgement that conducting IPA research with people for whom English is not their first language, requires that IPA guidelines are adapted when researching other groups. The present study represents one such adaptation. Smith argues that if the gains from speaking to a particular group sufficiently outweigh the costs from not speaking the same language, IPA studies involving interpreters and translators are warranted. Given the dearth of understanding around the aims of this Study, my adapted IPA approach is clearly warranted.

Finally, it is necessary to clarify that my analyses of the Study IIIa interviews that were conducted entirely in Punjabi, clearly do not constitute secondary data-analysis, according to Temple et al.'s (2006) definition – which involves the re-use of existing, often archived 'second-hand' data. Similarly, I fulfil the criteria of Primary Researcher, as I have *“develop[ed] an intimate bond with the material collected, ... have designed the framework, immersed [myself] in the field, and drawn on personal grounded insights to make analytic*

*interpretations"* (pg.2) and therefore I am clearly in full possession of the 'contextual production' of the study (Temple et al., 2006).

### 8.2.3 Challenges

During the course of this research, pragmatic barriers arose that required careful treatment to ensure successful completion of these Studies.

The need to identify potential barriers to ME people attending EPP, which could then be addressed and so prevent further exacerbation of health inequalities, was recognised at a very early stage of the Course's implementation. So cutting-edge was this initial phase of research that it took approximately eight months to recruit the five White tutors who had delivered EPP to a South Asian attendee. This protracted data-gathering was exacerbated when the EPP BME Lead necessarily took six months' leave, followed by a staged return to work. This meant that no South Asian-language EPPs were delivered, and no new tutors, including South Asians, were recruited. As no-one else at the collaborating NHS Trust could deputise, this effectively halted Study II recruitment. I used this time proactively, to continue gathering as much background information as possible (as reported in Appendix One) and was able to undertake detailed analysis of the interview transcripts that I had, and start disseminating my Findings. These unavoidable delays necessitated that I sought external funding, as it was evident that the University Studentship would expire prior to completion of the PhD. Thus, the setbacks were to my advantage in the long-term, as, with my Team's support, I successfully applied for and was awarded the Arthritis Research Campaign's Educational Research Fellowship.

Following her return to full-time work, the EPP BME Lead advised that the Punjabi Sikh women participants for my second phase of research were happy to be interviewed at the Community Centre that they attend every Monday morning.

The Punjabi EPP was originally scheduled to run September-October 2007, but was not actually delivered until May-June 2008, making the post-Punjabi EPP interviews impossible for eight months. I found reasons to contact the EPP BME Lead with relevant information (e.g. from the Minority Ethnic Health Discussion Forum), so as to maintain a positive working relationship. However, I used this delay as an opportunity to write-up and disseminate Study II findings as widely as possible, and successfully wrote my first published paper – see Appendix 4.1 for details.

Challenges also arose during the interviews themselves. I found the South Asian community-members were less formally constrained during this research activity than the tutors had been, and I experienced interruptions, digressions etc. I overcame by accepting that a flexible approach was required: if 11 a.m. is tea-and-cake time at the Community Centre, then interviews can pause!

The room in the Community Centre was used only occasionally and consequently was furnished very sparsely. With no carpet or curtains, and only hard chairs and tables, our voices echoed during the interviews, and the quality of the resultant audio data was very poor. This made transcription, which was already highly complex as discussed earlier, considerably more difficult and time-consuming than in previous interviews. Digital enhancement of the audio files helped, but did not eliminate the echo entirely. My efforts to overcome this issue by undertaking Study IIIb interviews elsewhere were resisted by participants; the same challenge therefore arose again. In anticipation I took steps within the interview room to reduce the echoes, for example by placing the recording equipment upon an item of clothing. This, and digital enhancement of the audio files again improved the quality, but did not eliminate the problem.

This, once more, had a time implication, as the Study IIIb interpreter/translator had no prior experience of transcribing interview data. This compounded the data-quality issue, in addition to the substantial time that translating the



interview data would necessarily take. These translated transcripts took over four months from interview to receipt. I again adopted a positive approach to this, using the time to write-up and disseminate Study IIIa (please see Appendix Four).

Collectively, these examples demonstrate that the novelty of both the topic area and the methodology was particularly challenging. I endeavoured not to perceive these 'Challenges' as a 'barriers' (Pitchforth and van Teijlingen, 2005). No psychology research guidelines existed at the outset of this research, with issues around interpreters/translators only just starting to emerge in qualitative health psychology circles during my final year. Thus, complex decisions had to be made based on similar research from relevant disciplines; whilst time-consuming, the delays reported above afforded me the time to assimilate these varied research practices into the present work.

### **Personal development**

These pragmatic and methodological concerns were severely exacerbated by a series of personal and professional issues, including the closure of the research centre in which I was based, resulting in my forthcoming redundancy (at the time of writing). I dealt with these collective challenges by using elements of the psychology that I am involved in. Varying combinations of positive reinterpretation, social support, humour, positive self-talk, Action Planning/goal-setting and cognitive distraction techniques, which I either learned as an undergraduate, or during the course of the PhD, have allowed me to achieve the aims of this research. The apparently endless delays have resulted in my ability to 'let go' of the uncontrollable in life, and focus, through achievable goal-setting, on effecting subtle changes that will lead to my desired outcomes. I am less critical of myself; I am also now better placed to recognise when to ask for help. Finally, I have learned that patience is a life skill that can, occasionally, result in the achievement of the seemingly impossible.

#### 8.2.4 Reflexivity

An essential component in qualitative approaches is that of reflexivity: the extent to which my involvement influenced the research process and outcomes. Rather than attempting to diminish individual differences in experience and perception, as in quantitative approaches, reflexivity is encouraged in IPA research, acknowledging and exploring the researcher's role (Biggerstaff and Thompson, 2008). It is explicitly addressed, including the researcher's "research interests, theoretical groundings and why they sought to undertake this particular piece of research" (Brocki and Wearden, 2006, pg.13). Psychological rapport and emotional empathy with participants are required in interview studies and subjectivity is a useful resource during analysis (Wilkinson et al., 2004). The 'micro-psychological level of [data] analysis' (Osborn, 2005) is highly subjective and this, too, is acknowledged, as analysis cannot be done without the interpretative work by researcher (Osborn, 2005). This section therefore explicitly acknowledges that my personal thoughts and feelings are "legitimate components of the enquiry" (Biggerstaff and Thompson, 2008; pg.221).

At the outset of this study, as a White, middle-class, educated woman with no LTHC, I had little prior knowledge about the academic constructs of this research: ME health inequalities, arthritis, self-management. My initial understandings were obtained from reading the relevant research publications and through engagement with my Team; I would therefore have absorbed any publication bias at this early stage. With an undergraduate degree in Psychology, my dissertation was in the field of health psychology, confirming my existing interest. My long-standing interests in health perceptions and social justice issues possibly reflect facets of my upbringing and emphasis on political correctness in my schooling. My personal experiences with people from South Asian backgrounds was limited to a number of childhood friends and work colleagues; all were young English-speakers would likely be from middle class Gujarati Hindu families. I am aware that one of these families used home remedies, but am uncertain as to the extent of this. I had spent many years

volunteering at a youth club which sought to integrate disabled and able-bodied young people that adopted a socially inclusive approach. Furthermore, with two family-members having musculoskeletal conditions, I was aware of some of the implications of living with arthritis. These factors undoubtedly contributed to my interest in the PhD and in how I planned and undertook the work.

Of central import in the present thesis, is that of ethnicity. Sometimes a highly sensitive subject, it is entirely possible that as a White researcher working with, in three of the four Studies reported here, South Asian participants, my perceptions of them and vice versa were unintentionally biased by the difference. For example, Study II tutors seemed keen to appraise me and my motivations, as an interested party, in their South Asian culture and its potential role in EPP. However, this seems to have proved useful, as they could take dual perspective, as all were 'Westernised' (acculturated); indeed the difference seemingly encouraged tutors to be explicit in their explanations of cultural issues. If I were South Asian, assumptions may have been made about my inherent cultural understandings, which may not have resulted in such detailed accounts of the tutors' experiences. Indeed, opportunities for probing that could have led to deeper insights were occasionally missed during the Study IIIa interviews conducted in Punjabi, (How does God help you to get better?/ I recite God's name and go to the Gurdwara. At home, I recite God's name. / How did you feel when you were well ?) although I acknowledge that this happens when I conduct interviews. Similarly, in Study III, I was particularly concerned that my ethnicity and perceived status as an academic may actually represent barriers to the Punjabi Sikh women accepting me. In turn, this could result in participants being reticent to share their personal experiences.

However, the extensive steps that I had undertaken in rapport-building with the EPP BME Lead and many others (detailed in Appendix One), to ensure my CC

to undertake this research, ensured that no such problem arose. Indeed, my status as an 'outsider' appeared to enhance my credibility with community-members, who seemed genuinely appreciative of an opportunity to voice their opinions. Only in Study IIIb am I aware that a strong cultural barrier may have influenced outcomes: in Punjabi culture it is considered rude to criticize or complain about anything that has been given in goodwill - unaware of this, I had asked for participants' suggestions for EPP's improvement; responses were not forthcoming. It has been suggested to me since, that a useful technique for overcoming this issue is to ask 'What would Westerners think about...'!

Ethnicity was not an issue for Study I interviews, as the White tutors and I are from the same ethnic backgrounds. My socio-economic status was also less likely to be an issue in the first two Studies, as tutors and myself were likely to share similar, middle class, backgrounds. However, one Study I participant appeared to have issue with my perceived status, repeatedly mentioning her private education, having established that I am State educated, and name-dropping her consultant-friends. As neither was of any consequence to me or relevant the topics under discussion, I do not feel that this adversely influenced the interview process or data-analysis. However, had any participant known of my association with the research Team who were involved in EPP's pilot implementation, this may have produced distorted responses. For example, tutors may have given politically correct answers when asked to identify anything that is potentially problematic for ME attendees – given diversity of responses, this seems unlikely to have occurred.

Cultural competence training is widely advocated for health workers, for example for medical students (Godkin and Savageau, 2001), nurses (Wilson, 2004), counselling psychologists (Vera and Speight, 2003) and care workers (Papadopoulos et al., 2004). However, as a PhD student in Health Psychology, no CC training course could be located, including with my governing body. In her model for developing CC research, Papadopolous (2006 in Nazroo book)

proposed four constructs that provide a framework for training health professional to undertake CC research. I now outline each of these in turn, giving examples of how I endeavoured to become CC in my chosen area of research:

1. **Cultural awareness:** Researchers examine and challenge their personal 'value base' (p.84) to understand how they are socially constructed. This self-awareness of cultural identity reduces the likelihood of imposing their own culturally-situated beliefs upon the culture being studied (Papadopolous, 2006). The preceding paragraphs attempt to address this point
2. **Cultural knowledge:** Should be drawn from relevant disciplines including anthropology, sociology, history, psychology and biomedicine, and also include contact with people from the cultural groups of interest (Papadopolous, 2006). Chapter Two demonstrates the inter-disciplinary literature review that I undertook to ensure a broad knowledge around SA culture; as previously noted, however, this could have led to my absorbing publication biases.
3. **Cultural sensitivity:** comprises building trust, empathy, acceptance, communication skills, appropriateness and respect in inclusive research (Papadopolous, 2006). The extensive fieldwork that I undertook to equip myself with these tools, is detailed in Appendix One – e.g. the advice that I was given to be direct, so as not to appear inadvertently patronizing, whilst avoiding social taboos such as sex.
4. **Cultural competence:** Synthesising and applying the previous points in design, data collection, analysis, report-writing, and dissemination; challenging essentialist practice and previous research (Papadopolous, 2006). The Study Chapters Four – Seven detail the steps that I undertook in order to meet this criterion. I have taken great care not to assume that cultural differences exist that over-rode other aspects of participants accounts, highlighting that the SA were often more similar to, than different from, White research participants in comparable research.

Similarly, the need for ethnicity-specific research (rather than e.g. 'Asian' or SA) is highlighted throughout this thesis.

Finally, my own contact with this Team may be another potential source of bias. It could be assumed, for instance, that I would confirm to their previous, largely positive, findings around various elements of EPP. In order to overcome such an accusation, I have deliberately tried to adopt a critical approach throughout this work, which does not assume self-management or EPP are inherently acceptable to the Punjabi Sikh community. The number of potential barriers to South Asian EPP attendance, engagement, comprehension and subsequent performance of self-management behaviours that this thesis contains is a strong indication that I have overcome any such bias.

### **8.3 Thesis Implications**

#### **8.3.1 Policy, theoretical and methodological Implications**

The first Study identified interesting considerations around how delivering English-language courses to non-English speaking attendees with interpreters, might impact. As working with interpreters is something EPP tutors of all ethnicities might encounter, it appears appropriate for EPP-CiC to train tutors how to best do this.

Immediately following Study I, I spoke to the (then) EPP Lead at Coventry NHS Trust about my findings. She quickly recognised the need for tutors to be trained in Cultural Competence (CC), and proposed this to her management. EPP was then still NHS-funded, and sadly this suggestion was not taken up locally. This highlighted the urgent need for this study from the outset, and its ramifications for local policy-makers

Nationally, tutors are still not routinely trained in CC. However, the timing of my first peer-reviewed published paper coincided with the EPP-CiC's Director of Product Development and Quality formally acknowledging that the issue of ME

inequalities of access needed to be explicitly addressed. I was invited to submit an outline proposal to this end, detailed in section 8.4.2, which was agreed in principle and we now await a final decision. Thus, the first Study demonstrates its local and national policy relevance.

The central role of patients' literacy and health literacy, as highlighted in Study II and IIIa, is receiving increasing recognition in terms of the patient education agenda generally and in the EPP and Rheumatology worlds specifically. As a result of the present Study, discussions are underway to collaborate nationally on a project that examines ME health literacy amongst RA patients. Until the outcomes of such studies are known, EPP-CiC policy-makers may choose to produce Punjabi-language Course Manual as a short-term solution. **arc** include patient education as one of their three key research priorities, and acknowledge the need for the inclusion of patients in such research. The importance of my Study I and II findings to their education research policy was recognised by **arc**, who awarded me the Educational Research Fellowship to continue and extend Study III. Part of the funding included a small follow-on Study to specifically investigate Punjabi Sikh arthritis patients' educational preferences (not presented here).

A key finding of this thesis is the existence of traditional self-management practices and the acceptance of new ones as part of these Punjabi Sikh women's routines. Their extensive use of traditional Indian CAM, yoga, and the positive role of their Sikh religion and spiritual beliefs, have the potential to influence the health education agenda beyond self-management. This finding offers preliminary support for Bandura's (1999) argument that *"cultural context shapes how efficacy beliefs are developed, the purpose to which they are put, and the social arrangements through which they are best expressed"* (p.35). Participants' efficacy expectations - that they believed themselves capable of performing a traditional Indian health behaviour, in order to improve their arthritis – also moves Self Efficacy Theory forward, to include this group of previously unheard Punjabi Sikh Indian women. Similarly, the current works

represents a first step towards including people from SA backgrounds in Social Learning Theory, as participants evidently embraced the elements of the EPP that allowed them to learn vicariously from each other, and observe and model tutors' health behaviours. Theories of health psychology that do not routinely include a religion/spiritual component may need to consider this in future. These data suggest that EPP may present a template for Punjabi Sikh self-management education, which also has policy implications - but community-needs driven research is required (detailed in next section). The adaptation of the IPA approach to accommodate the need for interpreters and translators in the present Study, represents what is believed to be a methodological innovation.

The **arc** funding afforded me numerous opportunities to present my research findings at a number of prestigious local, national and international conferences – please see Appendix Four for full details. These were in the fields of rheumatology, psychology, methodological, health policy, healthcare communication or self-management. Thus the likely policy, theoretical and methodological implications arising from this applied interdisciplinary research, have been widely recognised.

### **8.3.2 Recommended Future Research**

The novel nature of much of the research presented in this Thesis has recognised the need for numerous further investigations across the interdisciplinary areas that are integrated within this Study. The most pertinent of these are considered briefly, before outlining other relevant research that this thesis has identified.

The need for EPP tutors to undergo routine CC training was clearly identified, both by tutors themselves, and through my data-analysis. As mentioned above, this has been formally recognised by EPP-CiC, and a research proposal to develop/design, pilot and evaluate CC training which will lead to the



development of a CC educational intervention for all EPP tutors, has been agreed in principal and we now await a final decision.

The current text-dependant delivery-mode of the EPP has also been recognised as an area warranting more research, in the present Study. In association with (less text-dependant) Punjabi Sikh community members, a tailored self-management educational intervention for people with low literacy/health literacy needs to be designed, piloted and evaluated. It could consider use of pictorial representations and audio/video delivery media, in addition to CC content. Initial evaluation may be elicited through interviews or Focus Groups; however this raises the issue of non-criticism amongst Punjabi Sikh people, highlighted earlier. Any quantitative evaluation would be highly complex, requiring the standard measures to be designed and validated for use amongst target groups (e.g. pain/fatigue/Quality of Life/Self-efficacy scales etc. – but see below), and amended or redesigned as necessary; the reasons for this are considered now.

Little is known about the relevance of many of these constructs that have historically been used to evaluate self-management interventions, amongst South Asians generally or Punjabi Sikh people specifically. Extensive foundation work may therefore be required to consider, for example, South Asian people's pain, to answer research questions as: why pain is reported as more severe and widespread amongst South Asians; whether existing pain scales actually measure the embodiment of distress; what accounts for gender differences in pain in South Asian groups. The answers to such questions could inform the development of measures for validation amongst South Asian groups. Similarly, little research evidence has rarely considered the South Asian fatigue experience, which is known to be debilitating amongst mainstream arthritis populations. The theoretical construct of self-efficacy that underpins EPP has again been largely overlooked amongst Punjabi Sikh groups and will prove vital for future theory-driven research.

South Asian people's medication perceptions and any relationship that these may have on their adherence/concordance and CAM usage would provide insight into another area which has hitherto been ignored by researchers. This may be related to factors such as South Asians' understandings around illness causation and their psychological illness representations; areas which have attracted only limited research attention. Potentially relevant to this, are the Punjabi Sikh women's religious practices and spiritual beliefs as self-management behaviours, which have similarly never been considered in the literature. In addition to illuminating how best to address the issue of medication on a tailored EPP, the provision of this knowledge would impact beyond the patient education domain.

Numerous other studies are required to answer questions arising from the present small-scale, exploratory, Study, which are summarised in Box 8.2, on the following page. This is not intended to be an exhaustive list, as the possibilities for such an under-researched area are extensive. The outcomes of such studies, undertaken through meaningful engagement with the target communities including people who do not speak English, may start to provide an evidence base about the psychological constructs, self-management experiences and requirements of Punjabi Sikh groups. In turn, this may start to address one small area of minority ethnic health inequalities.

### 8.3.3 Research Outcomes

#### **Grant award**

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**Hipwell, A.E.,** Turner, A.P., Barlow, J.H. *Facilitators and barriers associated with psycho-educational self-management interventions among South Asian people with musculoskeletal conditions.* Arthritis Research Campaign Educational Research Fellowship Grant reference number 17882: £110,892; 3 years, 1st January 2007.

## Dissemination

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***Details of the extensive dissemination of these Findings that I have undertaken can be found in Appendix Five.***

Confirm that group learning is acceptable amongst this/other South Asian groups

Ascertain the role of caste amongst Punjabi Sikh groups in relation to group education

Establish whether potential Punjabi Sikh attendees are being deterred by concerns about disclosing personal information to other community-members

Seek evidence that the concepts of skills mastery and self-efficacy are psychological constructs that have practical applications for Punjabi Sikh people

Confirm walking for exercise and yoga are inherently acceptable self-management techniques amongst Punjabi Sikh women

Address how best to overcome social isolation in individuals from a group who are often perceived as 'collectivist' and self-supporting

Confirm a successful recruitment strategy, as suggested herein, amongst this population

Consider interviewing non-attenders on EPP, in order to identify further attendance barriers

Determine how best to elicit feedback about shortcomings the Punjabi EPP

Conduct longer-term follow-ups, for example, after 12 or 24 months

Further research with majority and minority participants, about their perceptions of payment for health education

### **Box 8.2 Suggestions for further research**

## 8.4 Thesis Conclusions

Psycho-educational self-management interventions such as the EPP improve physical and psychological outcomes for people who live with a LTHC. People from ME backgrounds experience increased prevalence and severity of many LTHCs. Prior to the commencement of this work, no-one from a South Asian background attended an EPP pilot course, in a multi-ethnic area of multiple deprivation in Coventry, raising concerns that the intervention may inadvertently serve to exacerbate these existing health inequalities.

This thesis has sought to address this, by exploring White and South Asian tutors' experiences of delivering EPP to South Asian people, to identify potential facilitators and barriers to EPP amongst these groups. Next, Punjabi Sikh women's experiences of living with and self-managing their arthritis, revealed barriers and facilitators to self-management, including attendance on EPP. The detrimental psychological and physical impact that arthritis has upon this homogenous group has been illustrated for the first time. However, this Study has provided a tantalising first glimpse into these women's worlds of arthritis self-management, revealing they were empowered and motivated to perform diverse behaviours to improve their lives. Using integrated combinations of prescription medication, and traditional Indian techniques including positive religious practices and spiritual beliefs prior to their EPP attendance, participants also adopted new skills that they learned when attending EPP. Whilst barriers to Punjabi Sikh women's attendance, engagement and performance of self-management behaviours were identified, facilitators that may serve to overcome such issues were also highlighted. Reporting psychological and physical benefits post-EPP, the present Study has established this group's inherent acceptance of the concept of self-management itself. Notwithstanding its current limitations, the likely appropriateness of EPP, subject to sensitive cultural tailoring, is confirmed.

This Study has generated vital knowledge, using participants' complex and multi-dimensional lived realities to enhance understanding of the involvement of psychological and physical features that contribute to Punjabi Sikh women's experiences of living with and self-managing arthritis, including EPP attendance. Developing a culturally tailored self-management intervention through meaningful engagement with the Punjabi Sikh community would address many of the issues raised, and may represent a small step towards reducing health inequalities amongst this group of people.

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# Appendix One: *Initial Fieldwork*

## **Appendix contents:**

### **A1.1 National fieldwork**

### **A1.2 Local fieldwork**

### **A1.3 Summary**

#### **A.1.1 National Fieldwork**

The summary of the relevant published literature in the areas of study, outlined in Chapter Two, demonstrated the underlying need for the current research. However, with only one published study addressing EPP with non-English speaking South Asians in the UK, a void in the evidence-base existed. A large body of lay knowledge also exists beyond the academic arena, with highly pertinent anecdotal evidence available from experienced health workers. This section outlines the national and local fieldwork that I undertook during the early stages of research, through a series of meetings, telephone conversations and emails. Contributors volunteered their personal views about the low BME attendance levels on EPP, and how this could or already had been overcome, and also how best to approach my research recruitment. Using these invaluable sources of detailed national and local insight, I sought to identify the best possible approach that this research should adopt, in order to achieve its aims.

#### **A1.1.1 EPP Leads' Experiences**

The following summarises the methods successfully used by EPP Leads at several PCTs to recruit South Asian people onto EPP, which were considered relevant when designing this research to attract South Asian participants.

Several EPP Leads had successfully organised non-English language EPPs by recruiting attendees at their existing community venues, e.g. a Sikh temple and an Asian Carer's group. Bilingual word-of-mouth recommendations and delivery in the relevant South Asian language encouraged attendance. Cultural adaptations included the production of Punjabi- and Hindi-language videos instead of the usual course-book, which worked particularly well for the exercise and diet aspects. This was produced locally as the number of dialects meant a central script did not work, although problems were experienced with Copyright approval.

Gender-specific courses in Bengali included a video but excluded the 'Living Wills'<sup>7</sup> section on Muslim-attended courses, replacing it with a 'Community Resources' session specifically designed for non-English speakers. Interestingly, Muslims who attended mixed-ethnicity, English-language courses that included the 'Living Wills' section, appeared keen to engage in discussion about this, with no apparent offence caused. Recruitment of high proportion of BME tutors (only 10% White) was attributed to using a photograph of the ethnically diverse course attendees in a free local newspaper.

The West Midlands EPP regional trainer found that by contacting religious and other 'important' community leaders, there was the potential for those individuals to exercise discretion (although not necessarily consciously/deliberately) as to whether or not they encouraged people to attend EPP, or which individuals to encourage. These individual community-members may then feel obliged to go, thus undermining the Programme's principles of voluntary attendance. It was also plausible that these senior community figures would be unaware of some of the most disempowered

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<sup>7</sup> A Living Will is a document stating a person's specific wishes about health care when for example, through ill health, s/he becomes unable to express her/himself. It is not legally binding, but acts as guidance for next of kin and health professionals. Some Muslims may consider this to be interfering with their destiny and the will of Allah.

individuals - for example housebound people who are sometimes not spoken about – or the issues these people face in their daily lives.

Clearly the current project could suffer similarly, if I were to inadvertently make an initial contact with a community leader who did not fully appreciate the potential benefits of EPP to the community. I was therefore advised to approach voluntary sector/grassroots workers, who may be well-placed to identify marginalised individuals who would therefore potentially benefit most from EPP. Finally, the regional trainer had found that asking the community/voluntary workers to present study materials to their groups, helped gain the group-members' trust.

### **A1.2 Translation of course material**

A senior DoH manager (AD) was responsible for overseeing the translation of EPP materials at the start of this research. AD recognised that whilst materials needed to be translated by someone who understood the conceptual content, this had to be balanced against attendees' need for simple and culturally relevant language to be used. Yet, by her own admission, “the first drafts... are not necessarily usable” (Dost, 2005; p.9). A.D. advised me that she had encountered problems including matching lay language to the technical text of the original materials and devising phrases to create the same meaning as the English term. This confirms the recognised complexity of the translation process. Active bilingual community-members in Leicester had volunteered to provide feedback on the later drafts of the Gujarati, Hindi and Punjabi materials.

The EPP Leads had also received informal feedback from tutors: problems existed with the translated course Manual and materials. The local bilingual tutors themselves sometimes experienced difficulty understanding the materials, as translations were in a 'high' (formal) form of the language that was also

inaccessible to some attendees. One EPP Lead described the Manuals as being written for The Times readership, when they needed to be aimed The Sun's patrons. The EPP Leads advised me that bilingual tutors hoped that translated Leaders' Manuals and attendees' course materials would be posted on the EPP website, thus ensuring easy national accessibility. However, the EPP Leads feared that the number of dialects of the minority languages, coupled with copyright concerns, may preclude this. The successful resolution to translation issues and cultural adaptation was considered likely to be central to the success of the EPP's national implementation for BME communities.

## **Summary**

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The insights that the EPP Leads across England provided me with raised my awareness of issues around the intervention that were not otherwise available. In combination with the published literature, as highlighted in Chapter Two, it allowed me to identify areas that warranted consideration in this exploratory Study. This national fieldwork alerted me to the imperative for appropriately targeted course materials to be developed, to allow effective EPP delivery by tutors, and comprehension of its content by South Asian attendees.

### **A1.2 Local Fieldwork**

#### **A1.2.1 South Asian Fieldworkers' Guidance**

In addition to EPP Leads across the country, I recognised the importance of local knowledge in determining the best way to reach potential participants for this Study. I therefore approached a number of healthcare workers in Coventry who had particular expertise around ethnicity.

I initially sought the advice of a British Muslim post-graduate health researcher (TU), with our discussions centring on the areas of religion and culture, as applicable both to EPP and to my research. TU advised me that Bangladeshi



Muslims believe that looking after the body is part of the Islamic religion, as the body is considered to be a gift from god that is returned to Allah after death. TU's understanding of Islam is that destiny and the Will of Allah are achieved by safeguarding health, including the use of preventative techniques. He considered attendance on EPP would fulfil this. My colleague felt that reports that some Muslim EPP attendees felt that the concept of self-management itself was interfering with destiny, or against the Will of Allah, might be attributable to varying local interpretations of the Q'uran. However, TU considered that talking to South Asian people about their health issues and religious beliefs were perfectly acceptable and unlikely to cause offence, assuming normal sensitivities were observed (I return to this shortly).

In terms of cultural issues I may face, TU advised that it is unusual for Muslim women to leave home alone. This had implications in terms of my recruitment of Muslim women as research participants, and also for EPP organisers to recruit course attendees: without chaperones, they may not be able to participate in either. TU also believed that it was possible that Muslim men may not want to see me alone, as this would not be appropriate between a Muslim man and woman.

TU further advised me that caste might potentially be an issue contributing to low South Asian attendance on EPP courses. If people of higher perceived social standing were attending EPP, it would not be considered appropriate for those of lower social status to volunteer to attend the course, and vice versa. If the local South Asians who had already attended EPP were from more affluent backgrounds, this issue may already have arisen in Coventry. (However, as the current project was addressing one particular geographical area, the research participants were likely to be from the same social background.) My colleague strongly advised against my asking direct questions about caste, as although not taboo, it is considered to be a sensitive subject.

My next contact (SC) was a Health Development Officer at Coventry City Council. Whilst SC had contacts at a local mosque, SC advised me that it is highly unusual for women to be allowed to enter. This was particularly pertinent, as Coventry PCT's EPP Lead had already informed me that it was unlikely that "the men at the mosque" would talk to me. I was also aware of an incident when an unaccompanied White female researcher encountered difficulties obtaining access at a local mosque, although she had pre-arranged the visit. SC very strongly suggested that I seriously considered the appropriateness of accessing local Muslim participants through the mosque, as it was entirely possible that I could inadvertently upset local sensibilities. As I did not have access to people from Muslim backgrounds through other avenues, this convergent advice effectively eliminated South Asians from Muslim backgrounds as research participants in this Study.

SC also suggested that conducting interviews in South Asians' community centres or in participants' homes, rather than at the Research Centre, would increase my recruitment of participants. She suggested that I was quite direct in my line of questioning so as to avoid appearing patronising, and that cultural taboos are broadly comparable to Western culture (avoid sex, infidelity, violence-related questions). SC believed that by making healthcare, including EPP, part of the social calendar involving the whole family, South Asian uptake could be improved.

#### **A1.2.2 Local EPP position**

At the outset of this Study, Coventry PCT employed three staff with responsibility for EPP: the PALS manager and EPP Lead, the EPP Co-ordinator, and, by late 2005, JS, Health Promotion Services (HPS) worker, whose remit later included increasing EPP attendance by BME people. The EPP Lead and JS suggested that I contact non-Muslim religious and voluntary organisations to find potential participants and also, that as EPP was growing in reputation among GPs, they may be prepared to help identify participants, should this be required.

JS had previous research experience with a South Asian population, examining diabetes management. In essence, her research found that a high level of ongoing support from Health Care Professionals (e.g. weekly telephone calls and monthly group meetings) improved medication adherence (Singh, 2004). She felt that the comparatively short-term nature of EPP courses might, therefore, need to be addressed in South Asian populations.

During the Pilot Phase of the EPP, none of the BME EPP attendees in Coventry came from the Foleshill electoral ward (Coventry PCT, 2005b). On the Index of Multiple Deprivation 2000, Foleshill was ranked the 182<sup>nd</sup> most deprived ward in England (ONS, 2003). Asian people represented 48.3% of Foleshill's population, compared to 11.3% in the whole of Coventry, which is also relatively high compared to England as a whole (4.4% – Office for National Statistics, 2001). However, the intervention was only available in English at that time.

At this Study's outset, seven trained EPP tutors were working in Coventry PCT's area; all are White. Although there was no BME EPP tutor in Coventry PCT's area at that time, the newly appointed HPS was expected to help address this. As approximately 15 courses were expected to run during the next 2½ years, it was anticipated that South Asian tutors might be identified and trained. This may, in turn, provide me with a population of potential research participants. Indeed, following the appointment of Coventry PCT's HPS, a Gujarati-speaking tutor and a Punjabi-speaking tutor were recruited. A one-day Gujarati 'taster' session was held at a community-funded day centre, which the HPS reported did not work well. The content was well received, but JS reported that the highly structured daily routine of the attendees and staff at the centre lacked the flexibility required to successfully deliver the session (e.g. having tea-breaks mid-session). Equally, this could be considered a reflection of EPP's inflexibility!

Attendees on the first Punjabi-language EPP in Foleshill were recruited through an advertisement that JS placed in the Foleshill community newsletter and on

the PCT's website; one person was referred by a hospital physiotherapist. It is noteworthy that no-one attended as a result of the information that JS sent out to community pharmacies and GP surgeries. JS agreed that word of mouth helped recruitment, with many (but not all) attendees on the Punjabi-language EPP knowing each other before attending.

Two bilingual Punjabi-speaking tutors delivered the course at a local church daycentre. Attendees' transport to the venue was provided according to need, at PCT's expense. One tutor was recruited from a local English-language course, the other, 'borrowed' from Leicester, had translated the Leader's Manual into Punjabi for the DoH and used this course to pilot it. Asking the same person to translate, pilot and feedback on the Punjabi manual appears to represent a flawed methodology: this may explain why other tutors experienced difficulty with the translation. Importantly, the **attendees'** course materials at the Punjabi-language EPP were only available in English. This could undermine potential benefits of the course, which stresses self-efficacy, if Punjabi-only speakers require family members to translate the English-language Manual for them. JS encourages English-speakers to attend English-language courses, due to the scarcity of Asian language-speaking tutors and to promote integration, although a free choice is offered. Similarly, I needed to ensure that my research materials were in a suitable format for my participants to understand.

JS received informal positive feedback about the first Punjabi EPP. One woman with severe depression told JS that the course had already helped her, whilst the wife of another attendee telephoned JS to report a noticeable improvement in her husband's condition. Men and women attended the course, with JS reporting that the mixed group worked well. No issues surrounding the concept of self-management were raised. A number of other South Asian language EPPs were planned, which may help to identify potential participants for this Study.

### **Local Guidance Summary**

The local BME health workers agreed that paying close attention to potential sensitivities about my gender and ethnicity, and being prepared to work around these issues, should enable me to successfully recruit research participants.

#### **A1.3 Summary**

Proactive PCTs nationally and locally started to successfully overcome some barriers to recruiting South Asian EPP attendees, by using innovative methods of marketing and tailoring the intervention. This, in turn, led to high numbers of South Asian volunteer tutors being recruited. In Coventry, work was ongoing with diverse communities to establish different South Asian groups' preferences, in order that as many people as possible from South Asian backgrounds are able to enjoy the benefits of EPP. These successful recruitment experiences were used to identify the best methodological approach to the current study, detailed in the Chapter Three.

This early advice that I obtained from both local and national sources was convergent: I should make contact with and follow the advice of local contacts who were familiar with the people with whom I was trying to engage; avoid exacerbating any existing local tensions and be sensitive to individuals as well as groups. A variety of recruitment methods had produced good EPP attendance from South Asian communities, especially when courses were delivered by a lay-tutor from the same ethnic background, and culturally and linguistically tailored.

## Appendix Two: Analytic Framework

### Appendix Contents:

#### A2.1 Worked example of descriptive analysis

#### A2.2 Worked example of interpretative analysis

#### A2.3 Worked example of phenomenological analysis

##### A2.1 Worked example of descriptive analysis

My descriptive level of analysis started with me identifying examples of 'what it is like' from the participants' accounts in the text (Larkin, Watts and Clifton, 2006), annotating my first descriptions of the participant's experiences, by hand, directly on the transcript. I later transferred my descriptive analyses into electronic format, creating a table that contained the participant's quote in the first column, and my descriptive analysis in the second. Participant numbers were used during analysis, with pseudonyms allocated at the write-up stage.

In the example below, my descriptive analysis highlights that the participant expresses her understanding that God helps her arthritis to improve when she prays. This occurs when she prays either at home, or when she goes to the Gurdwara to perform her religious practices:

<b><i>P14 Interview 3-way, with interpreter (Chapter 6, Phase IIa, Study 3)</i></b>	
<b><i>Quote, P.no, line no.s</i></b>	<b><i>Descriptive analysis</i></b>
<b><i>42-44 J:</i></b> How does God help you to get better?	<i>[leading Q, assumes God helps]</i>
<b><i>P14:</i></b> I recite God's name at the Gurdwara. At home, I recite God's name. That is it.	<i>Religious practices at home and temple help her feel better</i>

##### A2.2 Worked example of interpretative analysis

Having manually annotated an entire transcript with the descriptive level of analysis, during interpretative analysis, I then examined my descriptions and the transcript for alternative explanations and understandings, using more psychological and theoretical concepts and abstractions, as I attempted to understand participants' 'sense-making' (Larkin et al., 2006) of their experiences. This second order analysis allowed participants' data and my interpretations to be questioned critically for alternative meanings or understandings (Smith et al., 1999), again annotating the transcript with my thoughts and ideas, by hand. Caution was exercised to ensure that the interpretative nature of this process did not cause me to lose sight of participants' own words. I then transferred my interpretative analysis into electronic format, creating a third column on my table that contained my analysis, beside the participant's quote and the first order analysis.

The example below demonstrates that I moved beyond re-describing the participant's experience, and moved into interpreting her words by speculating that the mechanism through which prayer benefits her arthritis could be distraction. I also observe that the participant's location when she prays appears unrelated to the benefit that she understands it confers upon her. This is important as it removes the social support element of Gurdwara-attendance from this section of analysis, precisely pin-pointing the act of prayer itself.

<b><i>P14 Interview 3-way, with interpreter (Chapter 6, Phase IIa, Study 3)</i></b>		
<b><i>Quote, P.no, line no.s</i></b>	<b><i>Descriptive analysis</i></b>	<b><i>Interpretative</i></b>
<b><i>42-44 J: How does God help you to get better?</i></b>  <b><i>P14: I recite God's name at the Gurdwara. At home, I recite God's name. That is it.</i></b>	<i>[leading Q, assumes God helps]</i>  <i>Religious practices at home and temple help her feel better</i>	<i>Distraction thru Spiritual support she gets from praying (not only obtained by physically attending Gurdwara)</i>

### **A2.3 Worked example of phenomenological analysis**

In the final level of analysis, I sought to take the analysis to a higher level of abstraction, with deeper structures e.g. time, paradoxes, identified. I entered these connecting subthemes directly onto my analysis table, in a fourth column.

The following example shows how my phenomenological analyses of one participant's interview transcript identified prayer as a positive arthritis self-management technique:

<b><i>P14 Interview 3-way, with interpreter (Chapter 6, Phase IIa, Study 3)</i></b>			
<b><i>Quote, P.no, line no.s</i></b>	<b><i>Descriptive analysis</i></b>	<b><i>Interpretative</i></b>	<b><i>Phenomenological</i></b>
<b><i>42-44 J: How does God help you to get better?</i></b>  <b><i>P14: I recite God's name at the Gurdwara. At home, I recite God's name. That is it.</i></b>	<i>[leading Q, assumes God helps]</i>  <i>Religious practices at home and temple help her feel better</i>	<i>Distraction from pain thru Spiritual support she gets from praying? (not only obtained by physically attending Gurdwara)</i>	<i>Religious practices that form part of belief system provide spiritual support.</i>  <i>Prayer = positive SM</i>

I then identified clusters that were collated into themes of related topics (Eatough and Smith, 2006; Smith et al., 1999) in each participant's transcript, finding connections between the participant's data and my interpretations. For example, P14 returned to the role of God and self-management later in the interview. It can be seen below, that whilst a different line of questioning and answers provided detailed insight into this participant's meaning-making, the essence of her understanding is broadly similar to my above conclusion: that P14's spiritual beliefs represented a positive element of her arthritis self-management.

***P14 Interview 3-way, with interpreter (Chapter 6, Phase IIa, Study 3)***



<i><b>Quote, P.no, line no.s</b></i>	<i><b>Descriptive analysis</b></i>	<i><b>Interpretative</b></i>	<i><b>Phenomenological</b></i>
<p><b>92-101 J:</b> Do you think that self-help is due to God's grace?</p> <p><b>P14:</b> Yes. It is due to God's grace that you believe in God and God will shower blessing on you. [Pause] ...</p>	<p>[leading Q]</p> <p>She believes that its God's will that she believes in him, and he will reward her for her faith ['you' as in 'one/I']</p> <p>Does not consider herself instrumental/ relevant in effecting health behaviour change/ SM: this is a gift from God.</p>	<p>P14 may consider the ability to SM her arthritis as one of God's blessings?</p> <p>Fatalism – (external Locus of Control) disempowering??</p> <p>Or socially desirable answering?!?</p>	<p>Empowered within God's parameters/ boundaries?</p> <p>Spiritual beliefs = positive SM</p>

As both religious practices and spiritual beliefs form part of Sikhism, I identified these two quotes from this participant as potentially clustering together.

This cyclical process was repeated for every participant's transcript within each of the four studies, with newly emergent themes tested against previous transcripts and current themes of that study. In the final example, on the following page, this shows that I identified religion and spirituality again, in my analysis of another participant's interview transcript.

**P18: Interview 3-way, with interpreter (Chapter 6, Phase IIa, Study 3)**

<i>Quote, P.no, line no.s</i>	<i>Descriptive analysis</i>	<i>Interpretative</i>	<i>Phenomenological</i>
<p><b>A: 139-50:</b> <i>Ok. I am also interested in how being Punjabi affects your illness.</i></p> <p><b>J:</b></p> <p><b>P18:</b> <i>We just recite God's name. There is no God's fault. It's the body. Whatever happens, it's happening inside our body. Ya!</i></p> <p><b>J:</b></p> <p><b>A:</b> <i>Oh, I see. Does reciting God's name make you feel better?</i></p> <p><b>J:</b></p> <p><b>P18:</b> <i>I feel happy... All day. I am happy.</i></p> <p><b>J:</b></p>	<p><i>Prayer helps her illness</i></p> <p><i>Body malfunction not divine intervention/ punishment etc: biological</i></p> <p><i>Reciting God's name has positive beneficial effect</i></p>	<p><i>I asked about Punjabi culture, she replied about Sikhism. Answers in 2<sup>nd</sup> person.</i></p> <p><i>Doesn't say how/why prayer affects her arthritis</i></p> <p><i>Physical, not spiritual, causal inference/ understanding of illness construction</i></p> <p><i>(Leading question &gt; socially desirable answer?!)</i></p> <p><i>Therapeutic benefit of meditation?!?</i></p>	<p><i>[Unlike P14 – who considered it god's grace]</i></p> <p><i>[Like P14 – prayer = directly beneficial]</i></p> <p><i>Religion positive illness ?mediator? psychologically = positive SM</i></p>

The analysis presented here all contributed to the Findings presented in Chapter 6.4.1 'Punjabi Sikh experiences of living with arthritis', in the Major theme of 'Constraints vs. abundance' as an example within the subtheme of 'The abundant self-management palette'. Space restrictions precluded my presenting examples from every participant's contribution to each element of every subtheme in the Findings section of each study, hence much of the above is absent from the Findings, although its contribution is acknowledged.

## Appendix Three: *Ethics*

### Appendix Contents:

**A3.1 Study I, II & III Ethical approval**

**A3.2 Study I & II Inclusion/exclusion criteria**

**A3.3 Study I & II Information Sheet**

**A3.4 Study I & II Declaration of Informed Consent**

**A3.5 Study I & II Personal Details**

**A3.6 Study I & II Interview Schedule**

**A3.1 Study I, II & III Ethical Approval**

*Please see next page*

# COVENTRY UNIVERSITY - HIRI ETHICS COMMITTEE (HEC 1)

## POSTGRADUATE STUDENT & STAFF SUBMISSION

This form should be accompanied by the full research study proposal.

<b>Name</b>	Alison Hipwell		<b>E-mail</b>	a.hipwell@coventry.ac.uk	
<b>Designation</b>	PhD student, IRCH/HSS				
<b>1. Summary of proposal</b>	Longitudinal Interview design. <i>Phase I:</i> Expert Patient Programme lay-tutors will identify potential factors that encourage/inhibit people from ethnic minorities to attend the Programme. <i>Phase II:</i> Interviews with ethnic minority Programme attendees will (pre-course) establish life experiences that influenced attitudes to self-management and (post-course) how the Programme can be culturally enhanced. <i>Phase III:</i> Develop a theoretical model of the experience of living with and the self-management of long-term health conditions.				
<b>2. Sample of participants</b>	<i>Phase I:</i> 10 Expert Patient Programme (EPP) lay-tutors; <i>Phase II:</i> 24 people from ethnic minority backgrounds with a long-term health condition;				
<b>3. Site/s location</b>	Coventry University/Community Centres				
<b>Tick / Cross. "Where answered 'NO', please give reasons on separate page."</b>	<b>Yes</b>	<b>No*</b>			
<b>4. Scientific background, design, method and conduct of the study.</b>					
a) Have you given a justification for the research?	✓				
b) Have you commented on the appropriateness of the design, the perceived benefits, risks and inconveniences to participants?					
<b>5. Recruitment of participants.</b>					
Have you provided a comprehensive account of the characteristics of the population including the process for obtaining access as well the inclusion and exclusion criteria?	✓				
<b>6. Care and protection of research participants and researcher.</b>					
Have you given an account of any interventions, situations and risks which have the potential to cause harm to the participants and researchers?	✓				
<b>7. Access, storage, security and protection of participants' confidentiality.</b>					
Have you identified who will have access to the data and what measures have been taken to ensure confidentiality and compliance with the Data Protection Act?	✓				
<b>8. Informed Consent.</b>					
Have you given a full description of the process for requesting and obtaining informed consent?	✓				
<b>9. Community considerations.</b>					
Have you considered how this study will benefit the participants or the community from which they have been drawn?	✓				
<b>10. Participant information Sheet and consent form.</b>					
Are these attached?	✓				
<b>11. Source of External Funding</b>	Not applicable: School-funded studentship				
Signature of <u>student</u> / staff (take copies as appropriate)			Date	14/3/05	
Signature of Supervisor (take copies as appropriate)			Date	14/3/05	
Signature of Chairman	✓ [Signature]		Date	22.03.05	
Approved - Ethically a very sound proposal.					

Please complete in full and return to:

Research Manager, HIRI Ethics Committee, RCG17, Coventry University.

**COVENTRY UNIVERSITY  
SCHOOL OF HEALTH AND SOCIAL SCIENCES**

**STUDENT SUBMISSION TO SCHOOL RESEARCH ETHICS COMMITTEE**

**STUDENT'S NAME:** Alison Hipwell **COURSE:** MPhil/PhD  
**TITLE OF PROJECT:** Attitudes towards self-management of long-term health conditions among people from ethnic minority backgrounds

**Summary of the project in jargon-free language and in not more than 120 words**

**Sample:** Purposive - Phase I: 10 Expert Patient Programme (EPP) lay-tutors; Phase II: 24 people from ethnic minority backgrounds, eligible to attend EPP;

**Research site:** Coventry University and Community Centres in Coventry;

**Design:** Longitudinal interview;

**Methods of data collection:** Phase I: One-to-one semi-structured interviews with EPP lay-tutors; establish their experiences of participating in and running the course. Phase II: One-to-one semi-structured interviews with 24 people from ethnic minority backgrounds, interviewed before and after attending EPP. Examine facilitators and barriers to EPP's implementation, cultural appropriateness of course material and recruitment strategies. Interpretative Biographical Analysis.

**Access arrangements:** Phase I: Personal referrals; Phase II: Coventry City Council's Health Development Officer to facilitate access to local community representatives and then potential participants.

- Will the project involve patients (clients), health professionals, and/or patient (client) data and/or health professional data? yes ☐ no ☒
- Will any invasive procedure be employed in the research? yes ☐ no ☒
- Is there a risk of physical discomfort to those taking part? yes ☐ no ☒
- Is there a risk of psychological distress to those taking part? yes ☐ no ☒
- Will specific individuals or institutions (other than the University) be identifiable through data published or otherwise made available? yes ☐ no ☒
- Is it intended to seek informed consent from each participant (or from his or her parent or guardian)? yes ☒ no ☐

Student's signature

Date...14/3/05

Supervisor's signature

Date...14/3/05

**FOR COMMITTEE USE**

Immediate approval ..... ✓

Referral to appropriate Research Governance Committee .....

Referral to Local Research Ethics Committee .....

Referral to full School Research Ethics Committee .....

Decision pending receipt of further information (specify below)

Committee Member's Signature

Date...22/03/05

### A3.2 Study I & II Inclusion/exclusion criteria

#### **Inclusion Criteria:**

- Aged over 18 years;
- Is a trained EPP tutor;
- Has delivered an EPP course to one or more attendee identified as from a South Asian background;
- Speaks English;
- Is able to give fully informed consent.

#### **Exclusion Criteria:**

- Becomes unfit to participate (e.g. cognitive impairment, physical deterioration);
- Withdraws informed consent for any reason.

### A3.3 Study I & II Information Sheet

*(for Study I and II tutors, v3)*

**Study Title: Self-Management of Long-Term Health Conditions among People from Ethnic Minority Backgrounds.**

**Invitation:** We are inviting you to take part in a study that is part of a three year PhD (doctoral research degree) at Coventry University. Before you decide if you want to take part, please read this Information Sheet so you understand why the research is being done and what it will involve. Ask us if you would like more details (contact details are at the bottom of the page).

**What is the purpose of this study?** The Expert Patients Programme helps people with long-term health conditions to understand and manage their condition. Research shows that people who attend the Expert Patients Programme are less tired, more active and feel more confident afterwards. It is run for the NHS by people who themselves have a long-term condition and so understand what it is like to live with such a condition. Currently, not many people from ethnic minority backgrounds go on the course in Coventry. This research aims to find out why this is.

**Why have I been chosen?** You have been chosen because you are an EPP tutor who has delivered a course to someone from a South Asian background. We are interested in what you think about why few people from ethnic minority backgrounds go on to the Expert Patients Programme. 23 other people are helping us with this stage of the research.

**Do I have to take part?** No. If you decide to take part, you will be given this Information Sheet to keep and will be asked to sign and return a Consent Sheet to say you agree to take part. You can withdraw from the study at any time without giving a reason, by contacting us (details at the bottom of the page).

**What will I have to do?** You are being asked to take part in a research interview, which will last around an hour. This will probably take place at Coventry University, or in your home. We will pay your travelling expenses. You will be asked about your experiences of living with a long-term health condition, what might encourage more people from ethnic minorities to go to the Expert Patients Programme and what might put this group off going. Before you start talking to the researcher, you will be given a form to fill in with your personal details. Only the Principal Researcher will see this form. The discussion will be recorded and put into writing.

Principal Researcher: Alison Hipwell - [a.hipwell@coventry.ac.uk](mailto:a.hipwell@coventry.ac.uk); 024 7688 7188

Study Director: Dr Andy Turner – [a.turner@coventry.ac.uk](mailto:a.turner@coventry.ac.uk); 024 7688 7459

Any paperwork produced by this research study (for example, for the Expert Patients Programme management) will refer to you by an identity (ID) number only (e.g. 'participant 5 attended one of these courses').

**What are the possible disadvantages of taking part?** None are expected.

**What are the possible advantages of taking part?** The views of everyone who talks to us will be considered carefully and used to suggest improvements to the Expert Patients Programme organisers (we will refer to you by ID number only). So your views may help others.



**Will anyone else know I have done this?** Only the principal researcher will have access to your personal details, the recording and the written copy of our conversation, which will be kept in locked filing cabinets. Your name or details will not be given to anyone. So your family, the Expert Patients Programme organisers, your GP (doctor's surgery), hospital specialist etc. will not know that you have done this. No-one from your community will be told who has taken part. The recordings will be erased at the end of the study (approx. November 2007). The Data Protection Act (1998) will be followed at all times.

**What happens to the results of the study?** A summary of the results will be sent to all participants. The research findings will also be passed to the local and national Expert Patients Programme management, so they can see what needs to be done to help people from ethnic minority backgrounds. The results may also be published at professional conferences and in professional journals (you will be identified by ID number only).

**Who is organising and funding the research?** This PhD is being organised and funded by the School of Health and Social Sciences at Coventry University.

**I have some questions. Whom can I ask?** If you have any questions, now or during the research, please contact the principal researcher, Alison Hipwell, telephone (024) 7688 7188, or email [a.hipwell@coventry.ac.uk](mailto:a.hipwell@coventry.ac.uk).

**What if something goes wrong?** If you are unhappy about any aspect of this study, you may complain to the study director, Dr Andy Turner by telephone (024) 7688 7459 or email [a.turner@coventry.ac.uk](mailto:a.turner@coventry.ac.uk).

**What do I do now?** If you want to take part in this research, please sign both copies of the Declaration of Informed Consent. Keep one copy for your records with this Information Sheet and return the other in the envelope provided (it does not need a stamp).

**Thank you for reading this!**

Principal Researcher: Alison Hipwell - [a.hipwell@coventry.ac.uk](mailto:a.hipwell@coventry.ac.uk); 024 7688 7188  
Study Director: Dr Andy Turner – [a.turner@coventry.ac.uk](mailto:a.turner@coventry.ac.uk); 024 7688 7459



### A3.4 Study I & II Declaration Of Informed Consent

(To be administered to all tutors. V2)

Participant ID number.....

Please tick ✓

1. I have read and understand the 'Tutor Information Sheet (v2)'. ☐
2. I understand that taking part in this study will involve me being interviewed. ☐
3. I understand that the discussions will be recorded and that the recordings will be destroyed at the end of the study. ☐
4. I understand that there are no known expected discomforts or risks involved in my participation in this study. ☐
5. I understand that I am free to withdraw from the study at any time, without giving a reason, by contacting the e-mail address or telephone number below. ☐

**I give my informed consent to take part in this study. I understand that although a record will be kept of my participation in the study, my data will be identified by a number only.**

Signed.....

Dated.....

Principal Researcher: Alison Hipwell - [a.hipwell@coventry.ac.uk](mailto:a.hipwell@coventry.ac.uk); 024 7688 7188

Study Director: Dr Andy Turner – [a.turner@coventry.ac.uk](mailto:a.turner@coventry.ac.uk); 024 7688 7459

### A3.5 Study I, II & III Personal Details

(To be administered to **all** participants v.2)

Please see A3.4.1 for Punjabi translation

**IN CONFIDENCE**

Participant ID number.....

1. Family name:.....

2. Given name:.....

This sheet will be stored separately from all other information, to protect

your anonymity

**IN CONFIDENCE**

Participant ID number.....

3. Date of birth: Month..... Year.....

4. Sex (please circle one):    Male/Female

5. Nature of your long-term health condition (Please tick all that apply):

Diabetes   ☐

Arthritis   ☐

Heart condition   ☐

High blood pressure  
(hypertension)   ☐

*Endometriosis* ☐

Cancer ☐

Other ☐  
(please state)

.....

6. Country of your family's origin (Please tick one):

*Northern Ireland* ☐

Bangladesh ☐

Other (please state) ☐

.....

7. Country of your birth (Please tick one):

*Northern Ireland* ☐

*Bangladesh* ☐

Other (please state) ☐ .....

***IN CONFIDENCE***

Participant ID number.....

8. *Language you speak most often (Please tick one):*

*Hindi* □

*Arabic* ☐

Other (please state) ☐

.....

9. *Second language most often spoken (Please tick one):*

*English* ☐

*Urdu* ☐

*Hindi* ☐

*Punjabi* ☐

*Gujarati* ☐

*Arabic* ☐

*Chinese* ☐

*Mandarin* ☐

*Other (please state)* ☐

.....

10. *Religion (please tick one):*

*Church of England* ☐

*Roman Catholic* ☐

*Muslim* ☐

*Hindu* ☐

*Sikh* ☐

*Buddhist* ☐

*Jewish* ☐

*Agnostic/don't know* ☐

*Atheist/none* ☐

*Other (please state)* ☐ .....

***Thank you for your help!***

### **A3.6 Study I & II Semi-structured Interview Schedule**

(To be administered to Study I and II Tutors v2)

#### **Living with a long-term health condition:**

1. Can you describe a typical day living with a long-term health condition? (Prompts: Examples of how it affects your daily life? Compared to how you were before becoming ill/other people who are well?)
2. Can you describe a good day living with a long-term health condition?
3. Can you describe a bad day living with a long-term health condition?
4. What single event summarises your experience of living with a long-term health condition? (e.g. fear of the future at diagnosis; frustration at waiting for hospital appointments/treatment; pride at overcoming problems faced)

5. How long had you had your condition before you went on the Expert Patients Programme? How long ago was that?
6. What encouraged you to go? (Prompts: Did you know anyone involved in it? Did you know someone who had been on it? Felt you had nothing to lose?)
7. How did you feel before you went to the first session? And afterwards?
8. Are you using any self-management strategies at the moment? Which ones? Do you feel they help you to cope with your condition? How?

**Being a tutor on an EPP course:**

9. What made you decide to become a tutor on the self-management course? (Please provide one or two specific examples)
10. Do you have any previous experience of voluntary or community work in the past? Please provide me with a brief list. (Prompt: Did this involve working with people from ethnic minority backgrounds?)
11. What would you say the benefits are of being a tutor? Please give an example of how the experience of being a tutor has helped you.
12. And what are the disadvantages?
13. What do you enjoy most about running the course? And what's least enjoyable?
14. What support do you need as a tutor?
15. Have you noticed any change in yourself since becoming a tutor?

**Ethnicity**

16. How do you communicate with participants from different ethnic backgrounds? What influence does your own background have on the course/participants?
17. What are the main needs of people from ethnic minority backgrounds, in terms of the Expert Patients Programme? If possible, please give me an example from your own experience.
18. Do you think the course is meeting those needs? How? Why/not? How might it be improved?
19. Would you change the course in any way, to help people from ethnic minority backgrounds? How? What? Why?
20. What do you think about a special module for people from ethnic minority backgrounds?

**General**

21. Is there anything you'd like to add that we haven't covered in the interview?

## Appendix Four: *Study III*

### **Appendix Contents:**

**A4.1 Study III Inclusion/exclusion criteria**

**A4.2 Study III Information Sheet**

**A4.3 Study III Declaration of Informed Consent**

**A4.5 Study III Interview Schedule Pre-EPP**

**A4.6 Study III Interview Schedule Post-EPP**

**A4.7 Study III Materials Translation Processes**

***Ethical approval for this study was obtained prior to the first study commencing – please see Appendix A3.1.***

### **A4.1 Study III Inclusion/exclusion Criteria**

#### ***Inclusion Criteria:***

- *Female;*
- *Aged over 18 years;*
- *Considers herself to be from a Punjabi Sikh background;*
- *Considers herself to have rheumatoid arthritis and/or osteoarthritis;*
- *Speaks English or Punjabi;*
- *Is able to give fully informed consent.*

#### ***Exclusion Criteria:***

- *Becomes unfit to participate (e.g. cognitive impairment, physical deterioration);*
- *Withdraws informed consent for any reason.*

## A4.2 Information Sheet

### A4.2.1 English

(for Study III pre- and post-course interviewees, v3)

#### **Study Title: Self-Management of Arthritis among People from South Asian Backgrounds.**

**Invitation:** We are inviting you to take part in a study that is part of a three year PhD (doctoral research project) at Coventry University. Before you decide if you want to take part, please read this Information Sheet so you understand why the research is being done and what it will involve. Ask us if you would like more details (our contact details are below).

**What is the purpose of this study?** The Expert Patients Programme helps people with long-term health conditions including arthritis to understand and manage their condition. Research shows that people who attend the Expert Patients Programme are less tired, more active and feel more confident afterwards. It is run for the NHS by people who themselves have a long-term condition and so understand what it is like to live with such a condition. Currently, not many people from South Asian backgrounds go on the course in Coventry. This research aims to find out why this is.

**Why have I been chosen?** You have been chosen because you are from a South Asian background and have arthritis. We are interested in what you think about why few people from South Asian backgrounds go on the Expert Patients Programme. 9 other people are helping us with this stage of the research.

**Do I have to take part?** No. If you decide to take part, you will be given this Information Sheet to keep and will be asked to sign and return a Consent Sheet to say you agree to take part. You can withdraw from the study at any time without giving a reason, by contacting us (details at the bottom of the page). A decision to withdraw or not to take part, will not affect your ability to join an Expert Patients Programme course, or to become a tutor.

**What will I have to do?** You are being asked to take part in two research interviews, which will last around an hour. This will probably take place at your community centre. We will pay your travelling expenses. You will be asked about your experiences of living with arthritis, what might encourage more people from South Asian backgrounds to go to the Expert Patients Programme and what might put people off going. Before you start talking to the researcher, you will be given a form to fill in with your personal details. Only the Principal Researcher will see this form. The discussion will be recorded and put into writing. Any paperwork produced by this research study (for example, for the Expert Patients Programme management) will refer to you by an identity (ID) number only (e.g. 'participant number 10'). Special Expert Patients Programme courses for people from South Asian backgrounds are currently being organised in Coventry.

If you decide you would like to attend one of these courses, we will contact you again after you have been on it, to interview you about your experience.

**What are the possible disadvantages of taking part?** None are expected.

**What are the possible advantages of taking part?** The views of everyone who talks to us will be considered carefully and used to suggest improvements to the Expert Patients Programme organisers (we will refer to you by ID number only). So your views may help others.

**Will anyone else know I have done this?** Only the principal researcher will have access to your personal details, the recording and the written copy of our conversation, which will be kept in locked filing cabinets. Your name or details will not be given to anyone. So your family, the Expert Patients Programme organisers, your GP (doctor's surgery), hospital specialist etc. will not know that you have done this. No-one from your community will be told who has taken part. The recordings will be erased at the end of the study (approx. November 2008). The Data Protection Act (1998) will be followed at all times.

**What happens to the results of the study?** A summary of the results will be sent to all participants, unless you tell us not to. The research findings will also be passed to the local and national Expert Patients Programme management, so they can see what needs to be done to help people from South Asian



backgrounds. The results may also be published at professional conferences and in professional journals (you will be identified by ID number only).

**Who is organising and funding the research?** This PhD is being organised and funded by the Faculty of Health and Life Sciences at Coventry University and the Arthritis Research Campaign.

**I have some questions. Whom can I ask?** If you have any questions, now or during the research, please contact the principal researcher, Alison Hipwell, telephone (024) 7688 7188, or email [a.hipwell@coventry.ac.uk](mailto:a.hipwell@coventry.ac.uk).

**What if something goes wrong?** If you are unhappy about any aspect of this study, please contact the study director, Dr Andy Turner by telephone (024) 7688 7459 or email [a.turner@coventry.ac.uk](mailto:a.turner@coventry.ac.uk).

**What do I do now?** If you want to take part in this research, please sign both copies of the Declaration of Informed Consent. Keep one copy for your records with this Information Sheet and return the other in the envelope provided (it does not need a stamp).

**Thank you for reading this!**

Principal Researcher: Alison Hipwell - [a.hipwell@coventry.ac.uk](mailto:a.hipwell@coventry.ac.uk); 024 7688 7188

Study Director: Dr Andy Turner – [a.turner@coventry.ac.uk](mailto:a.turner@coventry.ac.uk); 024 7688 7459

## ਪੜਾਅ - II ਸੂਚਨਾ ਸ਼ੀਟ

(ਕੋਰਸ ਤੋਂ ਪਹਿਲਾਂ ਅਤੇ ਕੋਰਸ ਤੋਂ ਬਾਦ ਇੰਟਰਵਿਊ ਦੇਣ ਵਾਲਿਆ ਲਈ , ਵੀ 3 )

**ਅਧਿਐਨ ਦਾ ਵਿਸ਼ਾ :** ਦੱਖਣੀ ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਵਾਲੇ ਲੋਕਾਂ ਦਾ ਹੱਡੀਆਂ ਦੇ ਦਰਦ ਸਬੰਧੀ ਸਿਹਤ ਸੰਭਾਲ ਬਾਰੇ ।

**ਸੱਦਾ ਪੱਤਰ :** ਅਸੀਂ ਤੁਹਾਨੂੰ ਕਾਵੈਂਟਰੀ ਯੂਨੀਵਰਸਿਟੀ ਦੇ ਤਿੰਨ ਸਾਲਾ ਪੀ. ਐੱਚ. ਡੀ. (ਖੋਜ ਯੋਜਨਾ ) ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸੱਦਾ ਦੇ ਰਹੇ ਹਾਂ । ਫੈਸਲਾ ਲੈਣ ਤੋਂ ਪਹਿਲਾਂ ਜੇ ਤੁਸੀਂ ਇਸ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣਾ ਹੈ, ਕ੍ਰਿਪਾ ਕਰਕੇ ਸੂਚਨਾ ਸ਼ੀਟ ਪੜ੍ਹੋ ਤਾਂ ਜੋ ਸਮਝ ਸਕੋ ਕਿਉਂ ਖੋਜ ਹੋ ਰਹੀ ਅਤੇ ਇਸ ਵਿੱਚ ਕੀ ਹੋਵੇਗਾ । ਜੇ ਤੁਸੀਂ ਹੋਰ ਜਾਣਕਾਰੀ ਲੈਣੀ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਸਾਡੇ ਕੋਲੋਂ ਪੁੱਛੋ (ਸਾਡੇ ਨਾਲ ਸੰਪਰਕ ਕਰਨ ਲਈ ਜਾਣਕਾਰੀ ਹੇਠਾਂ ਹੈ )

ਇਸ ਅਧਿਐਨ ਦਾ ਵਿਸ਼ਾ ਕੀ ਹੈ ? ਐਕਸਪਰਟ- ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਲੋਕਾਂ ਦੀਆਂ ਲੰਬੇ ਸਮੇਂ ਦੀਆਂ ਬੀਮਾਰੀਆਂ ਦੀ ਸਿਹਤ ਸੰਭਾਲ ਜਿਵੇਂ : ਜੋੜਾਂ ਦੇ ਦਰਦ ਆਦਿ ਨੂੰ ਸਮਝਣ ਲਈ ਅਤੇ ਉਸ ਦੀ ਦੇਖਭਾਲ ਕਰਨ ਵਿੱਚ ਮਦਦ ਕਰਦਾ ਹੈ । ਖੋਜ ਰਾਹੀਂ ਪਤਾ ਲੱਗਿਆ ਹੈ ਕਿ ਜੋ ਲੋਕ ਐਕਸਪਰਟ-ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਵਿੱਚ ਆਉਂਦੇ ਹਨ, ਉਹ ਬਾਅਦ ਵਿੱਚ ਚੁਸਤ, ਹੌਸਲੇ ਵਾਲੇ ਅਤੇ ਘੱਟ ਬੱਕੇ ਨਜ਼ਰ ਆਉਂਦੇ ਹਨ । ਇਹ ਪ੍ਰੋਗਰਾਮ ਲੋਕਾਂ ਵੱਲੋਂ ਐਨ ਐੱਚ ਐਸ ਦੇ ਲਈ ਚਲਾਇਆ ਜਾਂਦਾ ਹੈ ਤਾਂ ਜੋ ਜਿਹਨਾਂ ਨੂੰ ਲੰਬੇ ਸਮੇਂ ਦੀ ਬੀਮਾਰੀ ਹੈ ਉਹਨਾਂ ਨੂੰ ਪਤਾ ਹੈ ਕਿ ਇਸ ਹਾਲਤ ਵਿੱਚ ਰਹਿਣ ਨਾਲ ਕਿਵੇਂ ਮਹਿਸੂਸ ਹੁੰਦਾ ਹੈ । ਹੁਣ ਦੱਖਣ-ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਵਾਲੇ ਲੋਕ ਕਾਵੈਂਟਰੀ ਵਾਲੇ ਕੋਰਸ ਵਿੱਚ ਘੱਟ ਆਉਂਦੇ ਹਨ । ਇਹ ਅਧਿਐਨ ਇਹ ਜਾਣਨਾ ਚਾਹੁੰਦੀ ਹੈ ਕਿ ਇਹ ਕਿਉਂ ਹੈ ?

ਮੈਨੂੰ ਕਿਉਂ ਚੁਣਿਆ ਗਿਆ ਹੈ : ਤੁਸੀਂ ਦੱਖਣੀ-ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਵਾਲੇ ਹੋ ਅਤੇ ਜੋੜਾਂ ਦੀਆਂ ਦਰਦਾਂ ਦੇ ਮਰੀਜ਼ ਹੋਣ ਕਰਕੇ ਤੁਸੀਂ ਚੁਣੇ ਗਏ ਹੋ । ਅਸੀਂ ਇਹ ਵੀ ਜਾਣਨ ਦੇ ਇੱਛੁਕ ਹਾਂ ਕਿ ਦੱਖਣੀ-ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਵਾਲੇ ਲੋਕ ਐਕਸਪਰਟ-ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਦੇ ਕੋਰਸ ਵਿੱਚ ਘੱਟ ਹਿੱਸਾ ਕਿਉਂ ਲੈਂਦੇ ਹਨ । ਖੋਜ 9 ਹੋਰ ਲੋਕ ਵੀ ਇਸ ਅਧਿਐਨ ਵਿੱਚ ਹਿੱਸਾ ਲੈ ਰਹੇ ਹਨ ।

ਕੀ ਮੈਨੂੰ ਹਿੱਸਾ ਲੈਣਾ ਪਵੇਗਾ ? ਨਹੀਂ ਜੇ ਤੁਸੀਂ ਹਿੱਸਾ ਲੈਣ ਲਈ ਫੈਸਲਾ ਕਰ ਲਿਆ ਤਾਂ ਤੁਹਾਨੂੰ ਸੂਚਨਾ ਵਾਲੀ ਸ਼ੀਟ ਰੱਖਣ ਲਈ ਅਤੇ ਸਹਿਮਤੀ ਸ਼ੀਟ ਦਸਤਖਤ ਕਰਕੇ ਵਾਪਿਸ ਦੇਣੀ ਪਵੇਗੀ ਕਿ ਹਿੱਸਾ ਲੈਣ ਲਈ ਰਾਜ਼ੀ ਹਾਂ । ਤੁਸੀਂ ਬਿਨਾਂ ਕਿਸੇ ਕਾਰਨ ਦੱਸਣ ਤੋਂ ਹਿੱਸੇਦਾਰੀ ਵਾਪਿਸ ਲੈ ਸਕਦੇ ਹੋ । ਤੁਸੀਂ ਹੋਰ ਲਿਖੇ ਨੰਬਰ ਤੇ ਸੰਪਰਕ ਕਰ ਸਕਦੇ ਹੋ ਹਿੱਸਾ ਨਾ ਲੈਣ ਦਾ ਫੈਸਲਾ ਤੁਹਾਨੂੰ ਐਕਸਪਰਟ-ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਦੇ ਜਾਣ ਵਿੱਚ ਕੋਈ ਰੁਕਾਵਟ ਨਹੀਂ ਪਾਵੇਗਾ ਅਤੇ ਨਾ ਹੀ ਤੁਹਾਨੂੰ ਸਿੱਖਿਅਕ ਬਣਨ ਤੋਂ ਰੋਕੇਗਾ ।

ਮੈਨੂੰ ਕੀ ਕਰਨਾ ਚਾਹੀਦਾ ਹੈ ? ਤੁਹਾਨੂੰ ਖੋਜ ਇੰਟਰਵਿਊ ਦੇ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸੱਦਿਆ ਜਾਵੇਗਾ ਜੋ ਲੱਗਭਗ ਇੱਕ ਘੰਟਾ ਚੱਲੇਗੀ । ਇਹ ਤੁਹਾਡੀ ਕਮਿਊਨਿਟੀ ਸੈਂਟਰ ਵਿੱਚ ਹੋਵੇਗੀ ਅਤੇ ਤੁਹਾਨੂੰ ਆਉਣ-ਜਾਣ ਦਾ ਖਰਚਾ ਦਿੱਤਾ ਜਾਵੇਗਾ । ਤੁਹਾਡੇ ਜੋੜਾਂ ਦੇ ਦਰਦ ਦੇ ਤਜਰਬੇ ਬਾਰੇ ਤੁਹਾਡੇ ਕੋਲ ਪੁਛਿਆ ਜਾਵੇਗਾ । ਦੱਖਣੀ-ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਵਾਲੇ ਲੋਕਾਂ ਨੂੰ ਐਕਸਪਰਟ-ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਕੋਰਸ ਵਿੱਚ ਜਾਣ ਲਈ ਕਿਸੇ ਗੱਲ ਨਾਲ ਹੌਸਲਾ ਦਿੱਤਾ ਜਾਵੇ ਉਤੇ ਕਿਸ ਗੱਲ ਕਰਕੇ ਲੋਕ ਕੋਰਸ ਤੇ ਨਹੀਂ ਜਾਂਦੇ । ਖੋਜਕਰਤਾ ਨਾਲ ਗੱਲਬਾਤ ਕਰਨ ਤੋਂ ਪਹਿਲਾਂ ਤੁਹਾਨੂੰ ਆਪਣੇ ਨਿੱਜੀ ਵੇਰਵੇ ਭਰਨ ਲਈ ਫਾਰਮ ਦਿੱਤਾ ਜਾਵੇਗਾ । ਇਸ ਨੂੰ ਕੇਵਲ ਮੁੱਖ ਖੋਜ ਕਰਤਾ ਹੀ ਵੇਖੇਗਾ । ਇਹ ਗੱਲਬਾਤ ਰਿਕਾਰਡ ਕੀਤੀ ਜਾਵੇਗੀ ਅਤੇ ਫਿਰ ਲਿਖੀ ਜਾਵੇਗੀ । ਇਸ ਖੋਜ ਯੋਜਨਾ ਰਾਹੀਂ ਕਾਵੈਂਟਰੀ ਪੇਪਰ (ਜਿਵੇਂ ਐਕਸਪਰਟ-ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਦੇ ਪ੍ਰਬੰਧ ਵਾਸਤੇ) ਕੇਵਲ ਸ਼ਨਾਖਤੀ ਨੰਬਰ ਦੇ ਕੇ ਭੇਜਿਆ ਜਾਵੇਗਾ (ਜਿਵੇਂ ਹਿੱਸੇਦਾਰ ਨੰਬਰ 10) । ਸਪੈਸ਼ਲ ਐਕਸਪਰਟ-ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਦੱਖਣੀ-ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਵਾਲੇ ਲੋਕਾਂ ਲਈ ਕਾਵੈਂਟਰੀ ਵਿਖੇ ਹੁਣ ਪ੍ਰਬੰਧ ਕੀਤੇ ਜਾ ਰਹੇ ਹਨ । ਜਦੋਂ ਤੁਸੀਂ ਇਹ ਕੋਰਸ ਕਰ ਲਵੋਗੇ ਤਾਂ ਅਸੀਂ ਫੇਰ ਤੁਹਾਡੇ ਨਾਲ ਸੰਪਰਕ ਕਰਾਂਗੇ ਤਾਂ ਕਿ ਤੁਸੀਂ ਆਪਣੇ ਤਜਰਬੇ ਸਬੰਧੀ ਇੰਟਰਵਿਊ ਦਿਉ ।

(ਪ੍ਰਿੰਸੀਪਲ ਰਿਸਰਚ.ਐਲੀਸਨ ਹਿਪਵੈਲ-ਐ.ਹਿਪਵੈਲ@ਕਾਵੈਂਟਰੀ.ਐਸੀ.ਯੂਕੇ; 024 76 887188

ਸੱਟਡੀ ਡਾਇਰੈਕਟਰ.ਡਾ ਐਡੀ ਟਰਨਰ-ਐ.ਟਰਨਰ@ਕਾਵੈਂਟਰੀ.ਐਸੀ.ਯੂਕੇ; 024 7688 7459 )

ਐਲੀਸਨ ਹਿਪਵੈਲ ਨੈਤਿਕ ਪਰੋਟੋਕੋਲ

24 ਮਈ 2007 ਨੂੰ ਪਿਛਲੀ ਵਾਰ ਲਿਖਿਆ ਸੀ ।

ਹਿੱਸਾ ਲੈਣ ਵਿੱਚ ਕੀ ਹਾਨੀਆਂ ਹਨ ? ਆਸ ਹੈ ਕਿ ਕੋਈ ਨਹੀਂ ।

ਹਿੱਸਾ ਲੈਣ ਵਿੱਚ ਕੀ ਲਾਭ ਹਨ ? ਜੇ ਤੁਸੀਂ ਸਾਡੇ ਨਾਲ ਭੱਲਬਾਤ ਕਰੋਗੇ ਅਸੀਂ ਧਿਆਨ ਨਾਲ ਸੁਣਕੇ ਐਕਸਪਰਟ-ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਦੇ ਪ੍ਰਬੰਧਕਾਂ ਨੂੰ ਸੁਧਾਰ ਕਰਨ ਲਈ ਸੁਝਾਅ ਦੇਵਾਂਗੇ (ਤੁਹਾਡੀ ਪਹਿਚਾਨ ਸ਼ਨਾਖਤ ਨੰਬਰ ਨਾਲ ਹੀ ਕੀਤੀ ਜਾਵੇਗੀ) ਤਾਂ ਜੋ ਤੁਹਾਡੇ ਵਿਚਾਰਾਂ ਨਾਲ ਹੋਰਾਂ ਨੂੰ ਮੱਦਦ ਮਿਲ ਸਕੇ ।

ਕਿਸੇ ਹੋਰਨੂੰ ਪਤਾ ਹੈ ਕਿ ਮੈਂ ਕੀ ਕੀਤਾ ਹੈ ? ਤੁਹਾਡੇ ਨਿੱਜੀ ਵੇਰਵੇ ਬਾਰੇ ਕੇਵਲ ਮੁੱਖ ਖੋਜ ਕਰਤਾ ਦੀ ਹੀ ਪਹੁੰਚ ਹੋਵੇਗੀ, ਆਪਣੀ ਰਿਕਾਰਡ ਕੀਤੀ ਭੱਲਬਾਤ ਅਤੇ ਲਿਖਿਤ ਵੇਰਵੇ ਜਿੰਦਗੇ ਅੰਦਰ ਰੱਖਿਆ ਜਾਵੇਗਾ । ਤੁਹਾਡਾ ਨਾਂ ਅਤੇ ਨਿੱਜੀ ਵੇਰਵੇ ਕਿਸੇ ਨੂੰ ਨਹੀਂ ਦੱਸਿਆ ਜਾਵੇਗਾ । ਤੁਹਾਡੇ ਪਰਿਵਾਰ, ਐਕਸਪਰਟ-ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਦੇ ਪ੍ਰਬੰਧਕ, ਤੁਹਾਡਾ ਜੀ. ਪੀ. (ਦੀ ਸਰਜਰੀ), ਅਤੇ ਹਸਪਤਾਲ ਸਪੈਸ਼ਲਿਸਟ ਆਦਿ ਨੂੰ ਵੀ ਪਤਾ ਨਹੀਂ ਲੱਗੇਗਾ ਕਿ ਤੁਸੀਂ ਕੀ ਕਿਹਾ ਹੈ । ਨਾਂ ਹੀ ਤੁਹਾਡੀ ਬਰਾਦਰੀ (ਕਮਿਊਨਿਟੀ) ਨੂੰ ਦੱਸਿਆ ਜਾਵੇਗਾ ਕਿ ਤੁਸੀਂ ਇਸ ਵਿੱਚ ਹਿੱਸਾ ਲਿਆ ਹੈ । ਇਹ ਗਿਆਨ ਦਾ ਵਿਸ਼ਾ ਖਤਮ ਹੋਣ ਤੇ ਬਾਅਦ (ਨਵੰਬਰ-2008) ਤਕ ਰਿਕਾਰਡ ਖਤਮ ਕਰ ਦਿੱਤਾ ਜਾਵੇਗਾ ਅਤੇ ਡੈਟਾ ਪ੍ਰੋਟੈਕਸ਼ਨ ਐਕਟ, (1998) ਨੂੰ ਹਰ ਵਕਤ ਅਪਣਾਇਆ ਜਾਵੇਗਾ ।

ਅਧਿਐਨ ਵਿਸ਼ੇ ਦੇ ਨਤੀਜਿਆਂ ਦਾ ਕੀ ਕੀਤਾ ਜਾਵੇਗਾ ? ਜੇ ਤੁਸੀਂ ਨਾਂਹ ਨਹੀਂ ਕਰਦੇ ਤਾਂ ਸਾਰੇ ਨਤੀਜਿਆਂ ਦਾ ਖੁਲਾਸਾ ਸਾਰੇ ਹਿੱਸੇਦਾਰਾਂ ਨੂੰ ਭੇਜਿਆ ਜਾਵੇਗਾ । ਖੋਜ ਦੀ ਪ੍ਰਾਪਤੀ ਸਥਾਨਕ ਅਤੇ ਕੌਮੀ ਐਕਸਪਰਟ-ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਪ੍ਰਬੰਧਕ ਨੂੰ ਭੇਜੀ ਜਾਵੇਗੀ ਤਾਂ ਜੋ ਉਹ ਦੱਖਣੀ-ਏਸ਼ੀਆਈ ਪਿਛੇਕਤ ਵਾਲੇ ਲੋਕਾਂ ਦੀ ਮੱਦਦ ਲਈ ਕੀ ਕਰ ਸਕਦੇ ਹਨ । ਇਸ ਦੇ ਨਤੀਜੇ ਕੋਨਫਰੈਂਸ ਅਤੇ ਜਰਨਲ ਵਿੱਚ ਵੀ ਛਪੇ ਜਾ ਸਕਦੇ ਹਨ । (ਤੁਹਾਨੂੰ ਸ਼ਨਾਖਤੀ ਨੰਬਰ ਰਾਹੀਂ ਜਾਣਿਆ ਜਾਵੇਗਾ)

ਇਸ ਅਧਿਐਨ ਦਾ ਪ੍ਰਬੰਧ ਅਤੇ ਮਾਲੀ ਮੱਦਦ ਕੌਣ ਕਰਦਾ ਹੈ ? ਇਸ ਪੀ ਐਚ ਡੀ ਦਾ ਪ੍ਰਬੰਧ ਅਤੇ ਮਾਲੀ ਸਹਾਇਤਾ ਕਾਵੈਂਟਰੀ ਯੂਨੀਵਰਸਿਟੀ ਅਤੇ ਦ ਆਥਰਾਈਟਿਸ ਰਿਸਰਚ ਕੈਮਪੇਨ ਵਾਲੇ ਦ ਫੈਕਲਟੀ ਆਫ ਹੈਲਥ ਐਂਡ ਲਾਈਫ ਸਾਈਨਸੀਸ ਵਿਭਾਗ ਵੱਲੋਂ ਹੁੰਦੀ ਹੈ ।

ਮੇਰੇ ਕੁਝ ਸਵਾਲ ਪੁਛਨੇ ਹਨ ਕਿਸ ਨੂੰ ਪੁੱਛਾਂ ? ਖੋਜ ਦੇ ਦੌਰਾਨ ਜੇ ਤੁਸੀਂ ਕੁਝ ਪੁੱਛਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਤੁਸੀਂ ਮੁੱਖ ਖੋਜ ਕਰਤਾ ਐਲੀਸਨ ਹਿਪਵੈਲ ਨਾਲ ਟੈਲੀਫੋਨ ਨੰਬਰ (024) 7688 7188 ਜਾਂ ਈ-ਮੇਲ ਰਾਹੀਂ ਸੰਪਰਕ ਕਰ ਸਕਦੇ ਹੋ ।  
ਐ.ਹਿਪਵੈਲ @ਕਾਵੈਂਟਰੀ.ਐਸੀ.ਯੂਕੇ.

ਜੇ ਕੁਝ ਗ਼ਲਤ ਹੁੰਦਾ ਹੋਵੇ ? ਜੇ ਤੁਸੀਂ ਅਧਿਐਨ ਤੇ ਕਿਸੇ ਪੱਖੋਂ ਖੁਸ਼ ਨਹੀਂ ਤਾਂ ਸਟੱਫੀ ਡਾਇਰੈਕਟਰ, ਡਾ. ਐਂਡੀ ਟਰਨਰ ਨਾਲ ਟੈਲੀਫੋਨ ਨੰਬਰ (024) 7688 7459 ਜਾਂ ਈ-ਮੇਲ ਰਾਹੀਂ ਸੰਪਰਕ ਕਰ ਸਕਦੇ ਹੋ ।  
ਐ. ਟਰਨਰ@ਕਾਵੈਂਟਰੀ.ਐਸੀ.ਯੂਕੇ.

ਮੈਨੂੰ ਕੀ ਕਰਨਾ ਚਾਹੀਦਾ ਹੈ ? ਜੇ ਤੁਸੀਂ ਇਸ ਅਧਿਐਨ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਰਜ਼ਾਮੰਦੀ ਦੇ ਸਿਹਮਤੀ ਫਾਰਮ ਤੇ ਦਸਤਖਤ ਕਰੋ । ਇੱਕ ਕਾਪੀ ਆਪਣੇ ਰਿਕਾਰਡ ਲਈ ਸੂਚਨਾ ਪੱਤਰ ਸਮੇਤ ਰੱਖੋ ਤੇ ਦੂਸਰੀ ਕਾਪੀ ਲਿਫ਼ਾਫ਼ੇ ਵਿੱਚ ਪਾ ਕੇ ਵਾਪਸ ਕਰੋ (ਟਿਕਟ ਦੀ ਕੋਈ ਲੋੜ ਨਹੀਂ)

ਇਹ ਪੜਨ ਲਈ ਤੁਹਾਡਾ ਧੰਨਵਾਦ

(ਪ੍ਰਿੰਸੀਪਲ ਰਿਸਰਚ: ਐਲੀਸਨ ਹਿਪਵੈਲ- ਐ.ਹਿਪਵੈਲ@ਕਾਵੈਂਟਰੀ.ਐਸੀ.ਯੂਕੇ; 024 7688 7188  
ਸਟੱਫੀ ਡਾਇਰੈਕਟਰ: ਡਾ. ਐਂਡੀ ਟਰਨਰ- ਐ.ਟਰਨਰ@ਕਾਵੈਂਟਰੀ.ਐਸੀ.ਯੂਕੇ; 024 7688 7459

### A4.3 Declaration of Informed Consent

#### A4.3.1 English

*(To be administered Pre-course, to obtain consent from pre-and post-course interviewees - the same participants. V3)*

Participant ID number.....

*Please tick ✓*

1. *I have read and understand the 'Information Sheet (v3)'.* ☐
2. *I understand that taking part in this study will involve me being interviewed twice.* ☐
3. *I understand that the discussions will be recorded and that the recordings will be destroyed at the end of the study.* ☐
4. *I understand that there are no known expected discomforts or risks involved in my participation in this study.* ☐
5. *I understand that I am free to withdraw from the study at any time, without giving a reason, by contacting the e-mail address or telephone number below.* ☐

***If you would prefer to be interviewed in a language other than Punjabi, this can be arranged. Please state the language you wish to use in an interview: .....***

*I give my informed consent to take part in this study. I understand that although a record will be kept of my participation in the study, my data will be identified by a number only.*

**Signed**..... **Dated**.....

Principal Researcher: Alison Hipwell - [a.hipwell@coventry.ac.uk](mailto:a.hipwell@coventry.ac.uk); 024 7688 7188

Study Director: Dr Andy Turner – [a.turner@coventry.ac.uk](mailto:a.turner@coventry.ac.uk); 024 7688 7459

ਪੜਾਅ- II ਸਹਿਮਤੀ ਬਾਰੇ ਸੂਚਨਾ ਪੱਤਰ  
( Phase – II Declaration of Informed Consent )  
(ਕੋਰਸ ਕਰਨ ਤੋਂ ਪਹਿਲੇ, ਪਹਿਲੀ ਅਤੇ ਆਖਿਰੀ ਇੰਟਰਵਿਊ ਲਈ ਸਹਿਮਤੀ ਵੀ 3 ਦੇ ਹਿੱਸੇਦਾਰ।)

ਹਿੱਸੇਦਾਰ ਦਾ ਸਨਾਖਤੀ ਨੰਬਰ -----  
ਕ੍ਰਿਪਾ ਕਰਕੇ ਟਿਕਾ ਕਰੋ :

1. ਸੂਚਨਾ ਸ਼ੁੱਧ ਪੜ੍ਹੀ ਹੈ ਅਤੇ ਸਮਝ ਸਕਦਾ/ ਦੀ ਹਾਂ (ਵੀ 2 )
2. ਮੈਨੂੰ ਪਤਾ ਹੈ ਕਿ ਇਸ ਅਧਿਐਨ ਦੇ ਵਿਸ਼ੇ ਅਧੀਨ ਮੇਰੀ ਇੰਟਰਵਿਊ ਹੋਵੇਗੀ
3. ਮੈਨੂੰ ਪਤਾ ਹੈ ਕਿ ਇਸ ਅਧਿਐਨ ਬਾਰੇ, ਗੱਲਬਾਤ ਰਿਕਾਰਡ ਕੀਤੀ ਜਾਵੇਗੀ ਅਤੇ ਅੰਤ ਵਿੱਚ ਇਹ ਨਸ਼ਟ ਕਰ ਦਿੱਤੀ ਜਾਵੇਗੀ
4. ਮੈਨੂੰ ਪਤਾ ਹੈ ਇਸ ਅਧਿਐਨ ਬਾਰੇ ਹਿੱਸਾ ਲੈਣ ਲਈ ਕੋਈ ਬੇ-ਆਰਾਮੀ ਅਤੇ ਕੋਈ ਖ਼ਤਰਾ ਨਹੀਂ ਹੈ
5. ਮੈਨੂੰ ਇਹ ਵੀ ਪਤਾ ਹੈ ਕਿ ਮੈਂ ਇਸ ਅਧਿਐਨ ਵਿੱਚ ਭਾਗ ਲੈਣ ਤੋਂ ਨਾਂਹ ਕਰ ਸਕਦਾ/ ਦੀ ਹਾਂ ਅਤੇ ਮੈਨੂੰ ਇਸ ਦਾ ਕਾਰਨ ਨਹੀਂ ਦਸਣਾ ਪਵੇਗਾ ਮੈਂ ਇਹ ਹੇਠਾਂ ਲਿਖੇ ਟੈਲੀਫ਼ੋਨ ਜਾਂ ਈ-ਮੇਲ ਰਾਹੀਂ ਦਸ ਸਕਦਾ/ ਦੀ ਹਾਂ

ਜੇ ਤੁਸੀਂ ਪੰਜਾਬੀ ਤੋਂ ਇਲਾਵਾ ਕਿਸੇ ਹੋਰ ਬੋਲੀ ਵਿੱਚ ਇੰਟਰਵਿਊ ਦੇਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਇਸ ਦਾ ਪ੍ਰਬੰਧ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ । -----

ਮੈਂ ਇਸ ਗਿਆਨ ਦੇ ਵਿਸ਼ੇ ਵਿੱਚ ਭਾਗ ਲੈਣ ਲਈ ਆਪਣੀ ਸਹਿਮਤੀ ਦਿੰਦਾ/ ਦੀ ਹਾਂ । ਮੈਨੂੰ ਇਹ ਵੀ ਪਤਾ ਹੈ ਕਿ ਮੇਰੀ ਇੰਟਰਵਿਊ ਦਾ ਰਿਕਾਰਡ ਰੱਖਿਆ ਜਾਵੇਗਾ ਅਤੇ ਮੇਰੀ ਸਨਾਖਤ ਸਿਰਫ ਡੈਟਾ ਨੰਬਰ ਰਾਹੀਂ ਹੀ ਕੀਤੀ ਜਾਵੇਗੀ ।

ਸਾਖਰ -----

ਸਿੱਖ -----

ਸੰਪਰਕ ਕਰਤਾ : ਐਲੀਸਨ ਹਿਪਵੈਲ

02476 887188

ਸੰਪਰਕ ਡਾਇਰੈਕਟਰ : ਡਾ. ਐਂਡੀ ਟਰਨਰ

02476 887459

#### A4.4 Personal Details

English-literate Study III participants' personal details were collected using the same form as for Study I & II participants – please see A2.5.

#### A4.1 Punjabi

### ਪੜਾਅ - II ਨਿਜੀ ਵੇਰਵਾ

(ਕੋਰਸ ਕਰਨ ਤੋਂ ਪਹਿਲੇ ਇੰਟਰਵਿਊ ਦੇਣ ਵਾਲੇ ਬਾਰੇ ਜਾਣਕਾਰੀ ਇਕੱਠਾ ਕਰਨਾ- ਵੀ 3 ਦੇ ਉਹੀ ਹਿੱਸੇਦਾਰ )

### ਗੁਪਤ ਜਾਨਕਾਰੀ

ਹਿੱਸੇਦਾਰ ਦਾ ਸਨਾਖਤੀ ਨੰਬਰ -----

1. ਪਰਿਵਾਰਕ ਨਾਂ -----

2. ਅਸਲੀ ਨਾਂ -----

ਇਹ ਪਰਚਾ ਬਾਕੀ ਸਾਰੀ ਜਾਨਕਾਰੀ ਨਾਲੋਂ  
ਅਲੱਗ ਰੱਖਿਆ ਜਾਵੇਗਾ ਤਾਂ ਕਿ ਤੁਹਾਡੀ ਪਹਿਚਾਨ  
ਦੂਸਰਿਆਂ ਨੂੰ ਨਾ ਹੋਵੇ

## ਗੁਪਤ ਭੇਦ

ਹਿਸੇਦਾਰ ਦਾ ਸ਼ਨਾਖਤੀ ਨੰਬਰ-----

3. ਜਨਮ ਤਾਰੀਖ----- ਮਹੀਨਾ----- ਸਾਲ-----

4. ਲਿੰਗ : ਮਰਦ / ਔਰਤ (ਪਾਸੇ ਚੱਕਰ ਲਗਾਉਂਦੇ)

5. ਲੰਬੇ ਸਮੇਂ ਤੋਂ ਸਿਹਤ ਦੀ ਦਸ਼ਾ : ਕ੍ਰਿਪਾ ਕਰਕੇ ਟਿਕ ਕਰੋ।

ਜੋੜਾਂ ਦੀ ਸੋਜਿਸ਼ ☐ ਜੋੜਾਂ ਦਾ ਪੁਰਾਣਾ ਰੋਗ ☐ ਰੀੜ ਦੀ ਹੱਡੀ ਦਾ ਰੋਗ ☐

ਸ਼ੂਗਰ ☐ ਦਿਲ ਦੀ ਹਾਲਤ ☐ ਉੱਚ ਲਹੂ-ਦਾਬ ☐

ਧੱਫਤ ਜਾਂ ਚਰਮ ਰੋਗ ☐ ਦਮਾ ☐ ਬੱਚੇਦਾਨੀ ਦਾ ਰੋਗ ☐

ਕੈਂਸਰ ☐ ਮਨੋਵਿਗਿਆਨਕ ਰੋਗ ☐ ਕੋਈ ਹੋਰ ਰੋਗ ☐

6. ਪਰਿਵਾਰ ਦਾ ਮੁੱਢਲਾ ਦੇਸ਼ :

ਭਾਰਤ ☐ ਪਾਕਿਸਤਾਨ ☐ ਬੰਗਲਾ ਦੇਸ਼ ☐

ਇੰਗਲੈਂਡ ☐ ਸਕਾਟਲੈਂਡ ☐ ਵੇਲਜ਼ ☐

ਨਾਰਥ ਆਇਰਲੈਂਡ ☐ ਆਇਰਸ਼ ਗਣਤੰਤਰ ☐ ਚੀਨ ☐

ਪਤਾ ਨਹੀਂ ☐ ਕੋਈ ਹੋਰ -----

7. ਉਹ ਦੇਸ਼ ਜਿੱਥੇ ਜਨਮ ਹੋਇਆ :

ਭਾਰਤ ☐ ਪਾਕਿਸਤਾਨ ☐ ਬੰਗਲਾ ਦੇਸ਼ ☐

ਇੰਗਲੈਂਡ ☐ ਸਕਾਟਲੈਂਡ ☐ ਵੇਲਜ਼ ☐

ਨਾਰਥ ਆਇਰਲੈਂਡ ☐ ਆਇਰਸ਼ ਗਣਤੰਤਰ ☐ ਚੀਨ ☐



## ਗੁਪਤ ਜਾਣਕਾਰੀ

8. ਜਿਹੜੀ ਬੋਲੀ ਤੁਸੀਂ ਆਮ ਬੋਲਦੇ ਹੋ :

ਪੰਜਾਬੀ	<input type="checkbox"/>	ਅੰਗਰੇਜ਼ੀ	<input type="checkbox"/>	ਹਿੰਦੀ	<input type="checkbox"/>
ਉਰਦੂ	<input type="checkbox"/>	ਗੁਜਰਾਤੀ	<input type="checkbox"/>	ਅਰਬੀ	<input type="checkbox"/>
ਚੀਨੀ	<input type="checkbox"/>	ਮੈਨਡਰੀਨ	<input type="checkbox"/>	ਕੋਈ ਹੋਰ -----	

9. ਦੂਸਰੀ ਬੋਲੀ ਤੁਸੀਂ ਆਮ ਬੋਲਦੇ ਹੋ :

ਪੰਜਾਬੀ	<input type="checkbox"/>	ਅੰਗਰੇਜ਼ੀ	<input type="checkbox"/>	ਹਿੰਦੀ	<input type="checkbox"/>
ਉਰਦੂ	<input type="checkbox"/>	ਗੁਜਰਾਤੀ	<input type="checkbox"/>	ਅਰਬੀ	<input type="checkbox"/>
ਚੀਨੀ	<input type="checkbox"/>	ਮੈਨਡਰੀਨ	<input type="checkbox"/>	ਕੋਈ ਹੋਰ -----	

10. ਧਰਮ

ਸਿੱਖ	<input type="checkbox"/>	ਮੁਸਲਿਮ	<input type="checkbox"/>	ਹਿੰਦੂ	<input type="checkbox"/>
ਚਰਚ ਆਫ ਇੰਗਲੈਂਡ	<input type="checkbox"/>	ਰੋਮਨ ਕੈਥੋਲਿਕ	<input type="checkbox"/>	ਬੋਧੀ	<input type="checkbox"/>
ਜੀਊਸ਼	<input type="checkbox"/>	ਐਗਨੋਸਟਿਕ/ ਪਤਾ ਨਹੀਂ	<input type="checkbox"/>	ਕੋਈ ਹੋਰ/ਕਿਸੇ ਧਰਮ ਵਿੱਚ ਵਿਸ਼ਵਾਸ ਨਹੀਂ-----	

ਮੰਦਰ ਕਰਨ ਲਈ ਤੁਹਾਡਾ ਧੰਨਵਾਦ



## **A4.5 Semi-structured Interview Schedule Pre-EPP**

### **A4.5.1 English**

#### **Living with a long-term health condition:**

1. *What it is like to live with a long-term health condition? (Prompts: Typical day/good day/bad day; Compared to how you were before/other people?)*
2. *Describe a single event summarises your experience of living with a long-term health condition? (e.g. fear of the future at diagnosis; frustration at waiting for hospital appointments/treatment; pride at overcoming problems faced)*

#### **Self-management:**

3. *What ways have you found of making it easier to live with your long-term health condition? What? How has it helped? How could other people benefit from your tip?*  
If not, have you tried anyone else's suggestions to help living with your long-term health condition?
4. *Is it up to you to do things to improve your own quality of life? (Prompts: e.g. or up to family/doctors/deities)*
5. *How do you feel about self-help schemes generally? (Prompts: do they help some people, not others? Who? Why – cultural/religious influences)*
6. *What would encourage you to go on one? (Prompts: Do you know anyone involved in one? Do you know someone who has been on it? Feel you have nothing to lose? others from same cultural background/caste-class/gender/family etc.)*
7. *What might put you off going (e.g. transport/cost/ perceptions of who else attending – ethnicity/caste-class/gender, what expectations are of what expected to say/do)?*

8. *What sort of things would a self-help course need to cover, in order to help you?*
9. *Local courses are currently run by ordinary people who have long-term health conditions themselves. Do you think this is acceptable? (Or should the courses be run by doctors or nurses?)*

**Ethnicity**

10. *How do you think your cultural background affects your views about the self-management of health conditions?*
11. *How do you think your religious beliefs affect your views about the self-management of health conditions?*

**General:** *Is there anything you'd like to add that we haven't covered in the interview?*

ਪੜਾਅ-II

(ਆਰਜੀ ਇੰਟਰਵਿਊ ਦੀ ਸੂਚੀ ਵੀ 3) ਕੋਰਸ ਤੋਂ ਪਹਿਲਾਂ

ਜੋੜਾਂ ਦੇ ਦਰਦ ਨਾਲ ਰਹਿਣਾ :

1. ਜੋੜਾਂ ਦੇ ਦਰਦਾਂ ਨਾਲ ਜੀਨਾ ਤੁਹਾਨੂੰ ਕਿਸ ਤਰ੍ਹਾਂ ਲਗਦਾ ਹੈ ? (ਇਸ਼ਾਰੇ : ਖਾਸ ਦਿਨ/ ਚੰਗਾ ਦਿਨ/ ਮਾੜਾ/ ਦੂਜੇ ਲੋਕਾਂ ਦੇ ਮੁਕਾਬਲੇ) ਦਰਦਾਂ ਤੋਂ ਪਹਿਲਾਂ ਤੁਸੀਂ ਕਿਵੇਂ ਮਹਿਸੂਸ ਕਰਦੇ ਸੀ ?)

ਸਿਹਤ ਸੰਭਾਲ :

2. ਤੁਸੀਂ ਜੋੜਾਂ ਦੇ ਦਰਦ ਹੁੰਦਿਆਂ ਜੀਵਨ ਨੂੰ ਸੁਖਾਲਾ ਬਣਾਉਣ ਲਈ ਕਿਹੜੇ ਢੰਗ ਵਰਤੋ ਹਨ ? ਇਨ੍ਹਾਂ ਨੇ ਤੁਹਾਡਾ ਕਿਵੇਂ ਫਾਇਦਾ ਕੀਤਾ ਹੈ ? ਤੁਹਾਡੇ ਇਸ ਗੁਰ ਤੋਂ ਦੂਜੇ ਲੋਕ ਕਿਵੇਂ ਫਾਇਦਾ ਲੈ ਸਕਦੇ ਹਨ ? ਜੇ ਨਹੀਂ, ਤਾਂ ਕਿ ਤੁਸੀਂ ਕਿਸੇ ਦੇ ਸੁਝਾਅ ਵਰਤੋ ਹਨ ਜਿਸ ਨਾਲ ਤੁਹਾਨੂੰ ਜੋੜਾਂ ਦੇ ਦਰਦ ਨਾਲ ਜੀਨ ਵਿੱਚ ਮੱਦਦ ਮਿਲੀ ਹੋਵੇ ।
3. ਕੀ ਇਹ ਤੁਹਾਡੇ ਤੇ ਹੈ । ਕੀ ਤੁਸੀਂ ਜ਼ਿੰਦਗੀ ਦਾ ਸੁਧਾਰ ਆਪ ਕਰਦੇ ਹੋ ? (ਇਸ਼ਾਰੇ : ਕਿ ਇਹ ਪਰਿਵਾਰਕ ਤੇ ਨਿਰਭਰ ਕਰਦਾ ਹੈ/ ਡਾਕਟਰ/ ਪ੍ਰਮਾਤਮਾ ਦੀ ਕ੍ਰਿਪਾ ਨਾਲ )
4. ਤੁਸੀਂ ਆਪਣੀ ਮੱਦਦ ਖੁਦ ਕਰਨ ਵਾਲੀਆਂ ਸਕੀਮਾਂ ਤੋਂ ਕੀ ਸਮਝਦੇ ਹੋ ? (ਕੀ ਇਹ ਕੁਝ ਲੋਕਾਂ ਨੂੰ ਫਾਇਦਾ ਕਰਦੀਆਂ ਹਨ ਅਤੇ ਕਿਉਂ : ਸੱਭਿਆਚਾਰ ਕਾਰਨ/ ਧਾਰਮਿਕ ਖਿਆਲਾਂ ਕਰਕੇ)
5. ਕਿਸੇ ਇੱਕ ਸਕੀਮ ਵਿੱਚ ਜਾਣ ਲਈ ਤੁਹਾਡੀ ਕਿਵੇਂ ਹੋਸਲਾ ਅਫਜਾਈ ਕੀਤੀ ਜਾਵੇ ? (ਇਸ਼ਾਰੇ : ਕੀ ਤੁਸੀਂ ਕਿਸੇ ਨੂੰ ਜਾਣਦੇ ਹੋ ਜੋ ਕੀ ਤੁਸੀਂ ਕਿਸੇ ਨੂੰ ਜਾਣਦੇ ਹੋ ਜਿਸਨੇ ਇਹ ਸਕੀਮ ਕੀਤੀ ਹੈ / ਇੱਕੋ ਸੱਭਿਆਚਾਰ ਵਾਲੇ ਲੋਕ/ ਜਾਤ-ਪਾਤ/ ਲਿੰਗ/ ਪਰਿਵਾਰ)
6. ਕਿਹੜੇ ਕਾਰਨਾਂ ਕਰਕੇ ਤੁਸੀਂ ਇਨ੍ਹਾਂ ਸਕੀਮਾਂ ਤੇ ਨਹੀਂ ਜਾਂਦੇ ? (ਇਸ਼ਾਰੇ : ਆਵਾਜਾਈ ਦੇ ਸਾਧਨ/ ਕੀਮਤ ਜਾਂ/ਇਹ ਵਿਚਾਰ ਕਿ ਇਹ ਕਿਸ ਵਾਸਤੇ ਹੈ /ਨਸਲੀ ਲੱਛਣ/ ਜਾਤ-ਪਾਤ/ ਲਿੰਗ; ਤੁਹਾਡੀਆਂ ਕੀ ਇੱਛਾਵਾਂ ਹਨ ਅਤੇ ਤੁਹਾਡੇ ਤੇ ਕੀ ਆਸ ਰੱਖੀ ਜਾਂਦੀ ਹੈ ?
7. ਤੁਹਾਡੀ ਸਹਾਇਤਾ ਲਈ ਆਪਣੀ ਮੱਦਦ ਕਰਨ ਵਾਲੇ ਕੋਰਸ ਨੂੰ ਕਿਹੜੀਆਂ ਗੱਲਾਂ ਦਾ ਧਿਆਨ ਰੱਖਣਾ ਚਾਹੀਦਾ ਹੈ ?
8. ਸਥਾਨਕ ਕੋਰਸ ਕੇਵਲ ਉਹਨਾਂ ਲੋਕਾਂ ਵੱਲੋਂ ਹੀ ਚਲਾਏ ਜਾ ਰਹੇ ਹਨ ਜਿਨ੍ਹਾਂ ਨੂੰ ਖੁਦ ਲੰਬੇ ਸਮੇਂ ਤੋਂ ਸਿਹਤ ਸਬੰਧੀ ਤਕਲੀਫ਼ਾਂ ਹਨ । ਕੀ ਤੁਸੀਂ ਮੰਨਦੇ ਹੋ ਕਿ ਇਹ ਠੀਕ ਹੈ (ਜਾਂ ਇਹ ਕੋਰਸ ਕੋਈ ਡਾਕਟਰ ਜਾਂ ਨਰਸ ਚਲਾਵੇ ? )

ਨਸਲੀ ਲੱਛਣ

9. ਦੱਖਣੀ-ਏਸ਼ੀਆਈ ਹੋਣ ਦਾ ਤੁਹਾਡੇ ਜੋੜਾਂ ਦੇ ਦਰਦਾਂ ਸਬੰਧੀ ਆਪਣੇ ਆਪ ਦੀ ਸਿਹਤ ਸੰਭਾਲ ਤੇ ਕੀ ਅਸਰ ਪੈਂਦਾ ਹੈ ?
10. ਤੁਹਾਡੇ ਧਾਰਮਿਕ ਵਿਚਾਰਾਂ ਦਾ ਤੁਹਾਡੇ ਜੋੜਾਂ ਦੀ ਦਰਦ ਨੂੰ ਠੀਕ ਰਖਣ ਤੇ ਕੀ ਅਸਰ ਪੈਂਦਾ ਹੈ ?

ਆਮ : ਕੀ ਤੁਸੀਂ ਕੁਝ ਹੋਰ ਕਹਿਣਾ ਚਾਹੁੰਦੇ ਹੋ ਜੋ ਅਸੀਂ ਇਸ ਇੰਟਰਵਿਊ ਵਿੱਚ ਨਹੀਂ ਪੁੱਛਿਆ ?

*How would you feel , if you can't come .*

## **A4.6 Semi-structured Interview Schedule Post-EPP**

### **A4.6.1 English**

#### **Semi-structured Interview Schedule (Post-course)**

**(v3)**

##### **Living with arthritis:**

1. How long had you had arthritis before you went on the Expert Patients Programme?
2. What encouraged you to go?  
Prompts: Did you know anyone involved in it?  
Did you know someone who had been on it?  
Felt you had nothing to lose?
3. How did you feel before you went to the first session?  
e.g. expectations of what expected to say/do?  
And afterwards?
4. What self-management strategies are you using at the moment?  
Do you feel they help you to cope with your condition?  
How?

##### **Being a South Asian attendee on an EPP course:**

5. Have you ever been on a self-help course before? Can you provide me with a brief list?  
Prompt: Did this involve other people from South Asian backgrounds?
6. What would you say the benefits are from going on the Expert Patients Programme course?  
Can you give an example of how the experience of going has helped you?
7. And what are the disadvantages?  
e.g. getting to the venue, fear of failure, time taken etc.
8. What did you enjoy most about the course? And what was least enjoyable?
9. What changes have you noticed in yourself since going?

10. How do you think your South Asian background influences what you learnt from the course?

11. How well did the course fit around your own religious beliefs?

12. What might be the main needs of people from South Asian backgrounds, in terms of the self-management of arthritis?

Can you give me an example from your own experience?  
e.g. others on course from same cultural background/caste-class/gender/family etc.

13. How do you think the course is meeting those needs?

Why/not?

How might it be improved?

14. How would you change the course, to help people from South Asian backgrounds? Why?

15. What do you think about a special module for people from South Asian backgrounds?

**General:** Is there anything you'd like to add that we haven't covered in the interview?

## ਪੜਾਅ- II

(ਆਰਜ਼ੀ ਮੁਲਾਕਾਤ ਦੀ ਸੂਚੀ ਵੀ 3 ) (ਕੋਰਸ ਤੋਂ ਬਾਅਦ )

ਜੋੜਾਂ ਦੇ ਦਰਦ ਨਾਲ ਰਹਿਣਾ

1. ਐਕਸਪਰਟ ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਤੋਂ ਜਾਣ ਤੋਂ ਪਹਿਲਾਂ ਤੁਹਾਨੂੰ ਜੋੜਾਂ ਦਾ ਦਰਦ ਕਿੰਨੇ ਸਮੇਂ ਤੋਂ ਸੀ ?
2. ਐਕਸਪਰਟ ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਵਿੱਚ ਜਾਣ ਲਈ ਤੁਹਾਨੂੰ ਹੋਸਲਾ ਅਫ਼ਜ਼ਾਈ ਕਿਵੇਂ ਹੋਈ ? (ਇਸ਼ਾਰੇ: ਕਿ ਤੁਸੀਂ ਕਿਸੇ ਨੂੰ ਜਾਣਦੇ ਹੋ ਜੋ ਇਸ ਪ੍ਰੋਗਰਾਮ ਨਾਲ ਸਬੰਧਤ ਸੀ/ ਕੀ ਤੁਸੀਂ ਕਿਸੇ ਨੂੰ ਜਾਣਦੇ ਹੋ ਜਿਸ ਨੇ ਇਹ ਕੋਰਸ ਕੀਤਾ ਹੋਵੇ ?/ਮਹਿਸੂਸ ਕੀਤਾ ਹੋਵੇ ਕਿ ਇਸ ਵਿੱਚ ਜਾਣ ਵਿੱਚ ਕੋਈ ਨੁਕਸਾਨ ਨਹੀਂ )
3. ਪਹਿਲੇ ਸੈਸ਼ਨ ਵਿੱਚ ਜਾਣ ਤੋਂ ਪਹਿਲਾਂ ਤੁਸੀਂ ਕਿਵੇਂ ਮਹਿਸੂਸ ਕੀਤਾ ਸੀ ? (ਉਦਾਹਰਨ ਦੇ ਤੌਰ ਤੇ ਜਾਣ ਤੋਂ ਬਾਅਦ ਕੀ ਉਮੀਦ ਰੱਖਦੇ ਸੀ ਅਤੇ ਕੀ ਕਹਿਣਾ ਚਾਹੁੰਦੇ ਸੀ ਅਤੇ ਤਸੀ ਕੀ ਕੀਤਾ ?
4. ਹੁਣ ਤੁਸੀਂ ਆਪਣੀ ਸਿਹਤ ਸੰਭਾਲ ਲਈ ਕੀ-ਕੀ ਤਰੀਕੇ ਵਰਤਦੇ ਹੋ ? ਕੀ ਤੁਸੀਂ ਸਮਝਦੇ ਹੋ ਕਿ ਇਹ ਸਿਹਤ ਨੂੰ ਠੀਕ ਰੱਖਣ ਲਈ ਮੱਦਦ ਕਰਦੇ ਹਨ ਅਤੇ ਕਿਵੇਂ ?

ਦੱਖਣ-ਏਸ਼ੀਆਈ ਹੋਣ ਦੇ ਨਾਤੇ ਐਕਸਪਰਟ ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਵਿੱਚ ਜਾਣਾ :

5. ਖੁਦ ਦੀ ਮਦਦ ਕਰਨ ਵਾਲੇ ਕੋਰਸ ਵਿੱਚ ਕੀ ਤੁਸੀਂ ਕਦੀ ਪਹਿਲਾਂ ਗਏ ਸੀ ? ਕੀ ਤੁਸੀਂ ਇਸ ਬਾਰੇ ਮੈਨੂੰ ਛੋਟੀ ਸੂਚੀ ਦੇ ਸਕਦੇ ਹੋ ? ( ਇਸ਼ਾਰੇ : ਜਿਵੇਂ ਕਿ ਇਸ ਵਿੱਚ ਹੋਰ ਵੀ ਲੋਕ ਸਨ ਜੋ ਦੱਖਣ-ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਤੇ ਸਨ ? )
6. ਐਕਸਪਰਟ ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਕੋਰਸ ਵਿੱਚ ਜਾਣ ਦੇ ਕੀ ਫਾਇਦੇ ਹਨ ? ਕੀ ਤੁਸੀਂ ਕੋਈ ਉਦਾਹਰਣ ਦੇ ਸਕਦੇ ਹੋ ਕਿ ਇਸ ਤਜਰਬੇ ਤੋਂ ਤੁਹਾਨੂੰ ਕਿਵੇਂ ਮੱਦਦ ਮਿਲਦੀ ਹੈ ?
7. ਐਕਸਪਰਟ ਪੈਸੈਂਟ ਪ੍ਰੋਗਰਾਮ ਕੋਰਸ ਵਿੱਚ ਜਾਣ ਦੇ ਕੀ ਨੁਕਸਾਨ ਹਨ ? (ਇਸ਼ਾਰੇ : ਕੋਰਸ ਵਾਲੇ ਥਾਂ ਤੇ ਪਹੁੰਚਣਾ, ਫੋਲੂ ਹੋਣ ਦਾ ਡਰ, ਸਮੇਂ ਦੀ ਬਰਬਾਦੀ ਆਦਿ )
8. ਇਸ ਕੋਰਸ ਬਾਰੇ ਤੁਸੀਂ ਸਭ ਤੋਂ ਜਿਆਦਾ ਕਿਸ ਗੱਲ ਦਾ ਆਨੰਦ ਮਾਣਿਆ ? ਅਤੇ ਕਿਸ ਗੱਲ ਦਾ ਸਭ ਤੋਂ ਘੱਟ ਆਨੰਦ ਮਾਣਿਆ ?
9. ਜਦੋਂ ਤੁਸੀਂ ਇਸ ਕੋਰਸ ਵਿੱਚ ਜਾਦੇ ਹੋ ਤੁਸੀਂ ਆਪਣੇ ਵਿੱਚ ਕੀ ਤਬਦੀਲੀ ਮਹਿਸੂਸ ਕੀਤੀ ਹੈ ?
10. ਦੱਖਣੀ-ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਦਾ ਇਸ ਕੋਰਸ ਵਿੱਚ ਜੋ ਤੁਸੀਂ ਸਿਖਿਆ ਹੈ , ਤੁਹਾਡੇ ਵਿਚਾਰਾਂ ਤੇ ਕੀ ਅਸਰ ਪੈਂਦਾ ਹੈ ?
11. ਇਹ ਕੋਰਸ ਤੁਹਾਡੇ ਧਾਰਮਿਕ ਵਿਚਾਰਾਂ ਦੁਆਲੇ ਕਿਵੇਂ ਫਿਟ ਰਿਹਾ ?
12. ਜੋੜਾਂ ਦੇ ਦਰਦ ਦੀ ਸਿਹਤ ਸੰਭਾਲ ਲਈ ਦੱਖਣ-ਏਸ਼ੀਆਈ ਲੋਕਾਂ ਦੀਆਂ ਮੁੱਖ ਲੋੜਾਂ ਕੀ ਹਨ ? ਕੀ ਤੁਸੀਂ ਆਪਣੇ ਤਜਰਬੇ ਬਾਰੇ ਕੋਈ ਉਦਾਹਰਣ ਦੇ ਸਕਦੇ ਹੋ ? (ਜਿਵੇਂ ਕਿ ਇਸ ਕੋਰਸ ਤੋਂ ਇਕੋ ਜਿਹੇ ਸਭਿਆਚਾਰਕ/ ਜਾਤ-ਪਿਛੋਕੜ ਦੇ ਲੋਕ ਪਾਤ/ ਲਿੰਗ/ ਪਰਿਵਾਰਕ ਸਬੰਧ ਆਦਿ)
13. ਕੀ ਤੁਸੀਂ ਸਮਝਦੇ ਹੋ ਕਿ ਇਹ ਕੋਰਸ ਉਹਨਾਂ ਜ਼ਰੂਰਤਾਂ ਨੂੰ ਪੂਰਾ ਕਰਦਾ ਹੈ ? ਜੇ ਨਹੀਂ ਤਾਂ ਕਿਉਂ ? ਇਹ ਕਿਵੇਂ ਸੁਧਾਰਿਆ ਜਾ ਸਕਦਾ ਹੈ ?
14. ਦੱਖਣੀ ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਵਾਲੇ ਲੋਕਾਂ ਦੀ ਮੱਦਦ ਲਈ ਇਸ ਕੋਰਸ ਵਿੱਚ ਕੀ ਤਬਦੀਲੀ ਲਿਆਉਂਗੇ ਅਤੇ ਕਿਵੇਂ ?
15. ਦੱਖਣੀ ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਵਾਲੇ ਲੋਕਾਂ ਲਈ ਇਕ ਖਾਸ ਹਿੱਸਾ ਹੋਵੇ, ਇਸ ਬਾਰੇ ਤੁਸੀਂ ਕੀ ਸੋਚਦੇ ਹੋ ?

ਆਮ : ਕੀ ਤੁਸੀਂ ਕੁਝ ਹੋਰ ਕਹਿਣਾ ਚਾਹੁੰਦੇ ਹੋ ਜੋ ਅਸੀਂ ਇਸ ਇਨਟਰਵਿਊ ਵਿੱਚ ਨਹੀਂ ਪੁੱਛਿਆ ?

#### **A4.7: Study III Materials Translation Processes**

(v3)

*The materials need to be translated into Punjabi. As the cost of having all materials professionally translated is prohibitive, the following has been adapted from Bhopal et al. (2004) principles for adapting written research materials into different languages and Birbili's (2000) translating guidance:*

- *A bilingual person who understands the Punjabi language and culture will translate the study's Phase II materials into Punjabi, ensuring conceptual equivalence (not simple literal translation) is achieved;*
- *As the bilingual person may not be representative of the target population because of education, age, sex etc., a representative of the target population will assess meaning and acceptability of the translated materials and modifications will be suggested;*
- *The bilingual person will amend materials as appropriate, comparing translations with the original English-language materials, to ensure conceptual equivalence is maintained;*
- *A second bilingual person who understands the Punjabi language and culture will back-translate the materials from the Punjabi into English;*
- *The two bilingual people and the principal researcher will meet to discuss the back-translations, negotiating a "best fit" to ensure conceptual equivalence is maintained;*
- *The resultant materials will be piloted with at least two monolingual members of the target population (if possible) to check face and content validity, with further changes suggested if necessary;*
- *The bilingual people and the principal researcher will again discuss the suggested modifications and amend materials as appropriate, comparing translations with the original English-language materials, to ensure conceptual equivalence is maintained.*

## Appendix Five: *Dissemination*

### A5.1 Peer reviewed Research Publications: Journal article

**Hipwell, A.E.**, Turner, A.P., Barlow, J.H. (2008). 'We're not fully aware of their cultural needs': tutors' experiences of delivering the Expert Patients Programme to South Asian attendees. *Diversity in Health and Social Care* 5(4): 281-290. (removed for copyright reasons)





















## A5.2 Invited speaker

**Hipwell A** and McFarland L (2006). *IPA: Qualitative Data analysis*. Clinical Psychology Research Group, Royal Leamington Rehabilitation Hospital, 26th January 2006

**Hipwell A** and McFarland L (2007). *Interpretative Phenomenological Analysis*. Presented at Doing Research Together Event, Warwick Medical School, University of Warwick. Available from: [fac/med/research/hsri/wc-pcr/training/doingresearchtogether2006](http://fac.med/research/hsri/wc-pcr/training/doingresearchtogether2006)

**Hipwell A**, Turner A & Singh J (2007). 'Self-management of long-term health conditions and the role of the Expert Patient Programme for people from South Asian backgrounds'. 'Think Tank' Self-management Event, University of Salford.

**Hipwell AE** & Turner AP (2007). Applied Research Centre in Health and Lifestyle Interventions, Self-management Programme, *Exploring collaborative possibilities event*, Sheffield Hallam University.

**Hipwell, A. (2008)**. *Facilitators and barriers associated with psycho-educational self-management interventions among South Asian people with musculoskeletal conditions*. British Society for Rheumatology Education Special Interest Group Meeting, Joint British Society for Rheumatology & British Health Professionals in Rheumatology Annual Meeting, Liverpool ACC

**Hipwell AE (2009)**. *Painkillers, herbs, yoga and prayer: arthritis self-management practices from the perspectives of Punjabi Sikh women*. West Midlands Rheumatology Forum, 'Ethnicity in Rheumatic Disease', Birmingham Medical Institute, September 2009.

### A5.3 Peer-reviewed Research Publications: Oral Presentations

**Hipwell, A. E.,** Turner, A. P., & Barlow, J. H. (2007). Tutors' experiences of cultural issues in the Expert Patients Programme. *Health Psychology Review*, 1(Suppl. 1), 221.

**Hipwell, A. E.,** Turner, A. P., Barlow, J. H., & Adebajo, A. (2008). A qualitative examination of Punjabi Sikh women's experiences of living with and musculoskeletal conditions, and perceived barriers and facilitators to self-management education. *Rheumatology* 47(Suppl 2), 101.

**Hipwell, A. E.,** Turner, A. P., & Barlow, J. H. (2008). Punjabi Sikh women's experiences of arthritis: methodological issues around Interpretative Phenomenological Analysis. *Canadian Psychology*, 49(2a), 156 – 157.

**Hipwell, A.,** Turner, A., Barlow, J., and Adebajo, A. (2008). Punjabi Sikh women's experiences of living with and self-managing arthritis: A qualitative exploration. *Psychology and Health*, 23(Suppl 1), 143.

**Hipwell, A.,** Turner, A., Barlow, J., (2008). *A qualitative exploration of Punjabi Sikh women's experiences of living with and self-managing arthritis in the UK*. 2008 International Congress on Chronic Disease Self-management. 76-77. Hosted by AFV Centre for Rheumatic Diseases, The University of Melbourne, 26-28 November 2008.

**Hipwell, A.,** Turner, A., Barlow, J., (2009). *Researching Punjabi Sikh women's experiences of arthritis and understandings about self-management education: Methodological issues around Interpretative Phenomenological Analysis*. International Society of Critical Health Psychology 6th Biennial Conference, University of Lausanne, Switzerland.

**Hipwell, A.,** Turner, A., Barlow, J., and Adebajo, A. (2009). *Punjabi Sikh women's experiences of a psycho-educational self-management intervention in the UK: A qualitative exploration*. 23rd annual conference of the European Health Psychology Society, Pisa, Italy.

### A5.4 Peer-reviewed Research Publications: Poster Presentations

**Hipwell, A.E.,** Turner, A., Barlow, J., Wright, C. (2005). *Research Proposal: Attitudes towards Self-management of Long-Term Health Conditions among People from Ethnic Minority Backgrounds*. Presented at 'Cash and Care: Understanding the Evidence Base for Policy & Practice'; Social Policy Research Unit, University of York, 13th - 15th April.

**Hipwell, A.E.,** Turner, A., Barlow, J., Wright, C. (2005). The cultural appropriateness of the Expert Patients Programme: White tutors' views. *Proceedings of the British Psychological Society, Division of Health Psychology Annual Conference*, 14(1): 36. Leicester: British Psychological Society.

**Hipwell, A.E.,** Turner, A., Barlow, J., Wright, C. (2005). 'Expert Patients Programme for South Asian attendees: An Interpretative Phenomenological Analysis of a Punjabi Sikh tutor's experiences'. 10th International Interpretative Phenomenological Analysis Conference, Bristol University,

**Hipwell, A.E.,** Turner, A., Barlow, J., Wright, C. (2006). Inter-cultural Communication issues in delivering the Expert Patients Programme for South Asian attendees: Comparing White and South Asian tutors' views. *Proceedings of the European Association for Communication in Healthcare International Conference on Communication in Healthcare*, P24.01.

**Hipwell, A.E.,** AP Turner, JH Barlow, CC Wright (2006). *The cultural appropriateness of the Expert Patients Programme for South Asian attendees: South Asian tutors' views. Enhancing Self Care - The Evidence Base'*, Social Dimensions of Health Institute and Alliance for Self Care Research, Universities of Dundee & St Andrews ' West Park Conference Centre, Dundee, 3-5 May.

**Hipwell, A.E.,** AP Turner, JH Barlow, CC Wright (2006). *The cultural appropriateness of the Expert Patients Programme for South Asian attendees: A Punjabi Sikh tutor's experiences.* Economic Social Research Council 'Research Methods Festival', University of Oxford.

**Hipwell, A.E.,** Turner, A., Barlow, J. (2007). Tutors' experiences of cultural issues in the Expert Patients Programme. *Health Psychology Review*, 1(Supp1): 221. Leicester: British Psychological Society.

**Hipwell, A.,** Turner, A., Barlow, J., & Adebajo, A. (2007). "I have to take some Indian things to help me, like ginger": Case-study of a Punjabi Sikh woman's experience of musculoskeletal disease. Midland Rheumatology Society Autumn Meeting.

**Hipwell, A.,** Turner, A., Barlow, J., Adebajo, A. (2008). A qualitative examination of Punjabi Sikh women's experiences of living with and musculoskeletal conditions, and perceived barriers and facilitators to self-management education. *Rheumatology* 47(2): 101.

**Hipwell, A.E.,** Turner, A.P., Barlow, J.H. (2008). Punjabi Sikh women's experiences of arthritis: methodological issues around Interpretative Phenomenological Analysis. *Canadian Psychology* 49 (2a): 156 – 157.

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### **A5.5 Selected Non-peer review publications**

Educational Research Fellowship arc award featured on CU website Latest News & Events pages: 'Researcher awarded £111k grant for research into South Asian arthritis patients'. <http://www.coventry.ac.uk/latestnewsandevents/a/2770>

'Participate: the newsletter of Warwick & Coventry Primary Care Research Network (WC-PCR)' (2007) 3:2. Available from:

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Oral presentation at European Health Psychology Conference cited in Kirana, E. (2007). 'Conference Reflections'. *The European Health Psychologist*, 9(4): 80. Available from:

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Coventry University, Faculty of Health and Life Sciences, *Local Team Brief* (October 2008 & January 2009)

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